

**Understanding the Bereavement Experiences of Pakistani Women
following Infant Mortality**

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The candidate confirms that the work submitted is his/her own and that appropriate credit has been given where reference has been made to the work of others

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ABSTRACT

Introduction: The death of an infant is a source of profound grief (Boyle, 1997). Reactions to and adjustments following the loss are often connected with the social, cultural and political position of the mother (Boone, 1985). West African, Caribbean, Pakistani and Bangladeshi women, have been reported to experience the highest rate of infant mortality in the UK (ONS, 2014b). Dominant narratives of infant mortality revolve around genetic and individual lifestyle factors (Bunday, Alam, Kaur, Mir, & Lancashire, 1991; Parslow et al., 2009), with little exploration of the impact of this narrative on grieving minority women. In addition existing models of grief highlight a linear process involving dynamic progression through phases (Kubler-Ross & Kessler, 2005) or more recently the concept of ‘*continuing bonds*’ has emerged (Klass, Silverman, & Nickman, 2014). However little is known about the bereavement experience of Pakistani women, despite them experiencing the highest rates of infant mortality.

Method: Seven bereaved Pakistani women were interviewed about their experiences of infant mortality, using the Biographic Narrative Interview Method. Drawing on feminist and social critical narrative inquiry. the focus was on exploring how Pakistani women make sense of the loss and how their experiences and meaning-making are linked to social, cultural and political structures and discourses. The data was analysed using Framework Analysis. In addition, individual narrative portraits were developed for each woman.

Results: Six main narratives were identified from the group analysis. Pakistani women’s experience of infant mortality involved the telling of ‘*uncertain*’, ‘*powerless*’, ‘*grief*’ and ‘*transformative*’ narratives. Women demonstrated the interconnection between power, uncertainty, grief and transformation. Feeling powerless and uncertain exacerbated their grief whereas feeling empowered and supported to bring about change helped their grief to heal. Women also demonstrated that ‘*sense-making*’ was a key part of their bereavement experience, which was influenced by stories of blame, times when women noticed inconsistencies and their religion. Pakistani women’s bereavement experience was timeless and linked to their racial and religious position. Finally ‘*meeting our needs*’ included reflecting on the care that they received and how services could better meet their needs, particularly around the provision of psychological support, chaplaincy, specialist language support and BME women’s involvement in decision making bodies in services.

Discussion: The research highlights how Pakistani women challenge the master narratives of pregnancy and infant mortality. Their experiences of loss and bereavement can be similar as well as different from dominant discourses of loss, as well as more complex and uncertain than

some traditional Western models of grief. The study highlights the importance of considering the racial, gendered and religious position of minority women as they navigate health services following infant mortality. The research also indicates the importance of culturally sensitive psychological support post bereavement.

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INTRODUCTION

The focus of this study is on the bereavement experiences of Pakistani women following infant mortality. This chapter will introduce the literature in relation to the topic, beginning with defining what is meant by infant mortality and exploring some of the literature on the risk factors associated with infant mortality including biological as well as social and systemic factors. Women's experiences of maternity services in general and when infant death occurs will be considered. In addition the existing literature on Black Minority Ethnic (BME) women's experience of maternity services and infant mortality will be considered. Lastly this chapter will also explore the literature on the psychological sequelae following infant mortality, as well as existing models of grief and bereavement.

To begin the chapter will start by defining what is meant by the term '*infant mortality*'.

Infant Mortality

Definition and aetiology

Infant mortality is defined in UK policy as the death of a child less than one year of age that was born alive (ONS, 2013). Infant deaths (under 1 year) at various ages are defined as:

- perinatal (early neonatal deaths);
- neonatal (deaths under 28 days);
- post-neonatal (deaths between 28 days and 1 year). (ONS, 2013)

Therefore, infant mortality can occur during the neonatal, post neonatal and perinatal period. However some have argued that the definition of infant mortality is open to interpretation, mainly because very early deaths can be misclassified as stillbirths or late abortions (Rosano, Botto, Botting, & Mastroiacovo, 2000).

The causes of infant mortality are multifactorial and it is also true that a number of deaths remain unexplained. Unexplained deaths affecting this population include Sudden Infant Death Syndrome (SIDS). This is a form of infant mortality in which the cause of death remains unexplained following autopsy, death scene investigation and a medical history review (Blair, Sidebotham, Berry, Evans, & Fleming, 2006). Eight percent of all infant deaths remain unexplained or are classed as SIDS (ONS, 2014c). However a range of factors have been suggested to contribute to infant mortality e.g. maternal age and lifestyle (Chen et al., 2007; Wisborg, Kesmodel, Henriksen, Olsen, & Secher, 2001), obstetric complications (Filippi et al.,

2007), infections (Hortensia et al., 1997), prematurity (Callaghan, MacDorman, Rasmussen, Qin, & Lackritz, 2006), infants' sleep position (Gessner, Ives, & Perham-Hester, 2001), low birth weight (Pollack et al., 2000), congenital anomalies (Parslow et al., 2009), access to healthcare (Downe, Finlayson, Walsh, & Lavender, 2009) and parental mental health (Webb et al., 2010). However national cohort studies which have looked at infant mortality are limited by the fact that they often have a lack of data concerning the antecedents and circumstances around the death (Webb et al., 2010). Furthermore socio-economic status and deprivation has also been linked to infant mortality (Oakley, Maconochie, Doyle, Dattani, & Moser, 2009).

Rates of Infant Mortality in the UK

Rates of infant mortality are seen as a major indicator of the health of a nation (Norman, Gregory, Dorling, & Baker, 2008). Department of Health (DoH) figures show that 3,000 babies die every year in the UK before their first birthday and many more are stillborn or have long-term disabilities (DoH, 2010).

The ONS releases figures every year on the rates of infant mortality in the UK. The infant mortality rate is the number of infant deaths under the age of one measured against every 1,000 live births. Currently the rate is 3.9 per 1,000 live births (ONS, 2014b). However, although infant mortality rates in the UK are at an all-time low, significant disparities exist in terms of socio-economic status, area and ethnicity (DoH, 2010; ONS, 2014a).

In 2008, Professor Sir Michael Marmot was asked by the then Secretary of State for Health to chair an independent review to reduce health inequalities in England. The Marmot Review (2010) highlighted that deprivation, non-white ethnicity of the mother/infant and maternal age were independently associated with an increased risk of infant death. He concluded that:

“one quarter of all deaths under the age of one would potentially be avoided if all births had the same level of risk as those to women with the lowest level of deprivation”

(Marmot et al., 2010, p. 60)

The Review also concluded that reducing health inequalities would require action on six policy objectives:

1. Give every child the best start in life
2. Enable all children, young people and adults to maximise their capabilities and have control over their lives
3. Create fair employment and good work for all
4. Ensure healthy standard of living for all

5. Create and develop healthy and sustainable places and communities
6. Strengthen the role and impact of ill-health prevention

Though the Review highlighted considerable health inequalities and recommended key policy objectives, it has been argued that it failed to acknowledge and pay attention to ethnic inequality (Salway et al., 2010). Salway and colleagues (2010) argued that health inequality and life expectancy is closely linked to “*racialised hierarchies of exclusion*” and that health outcomes for some minority ethnic groups are worse than would be expected based solely on their social circumstances.

Social Exclusion and Infant Mortality

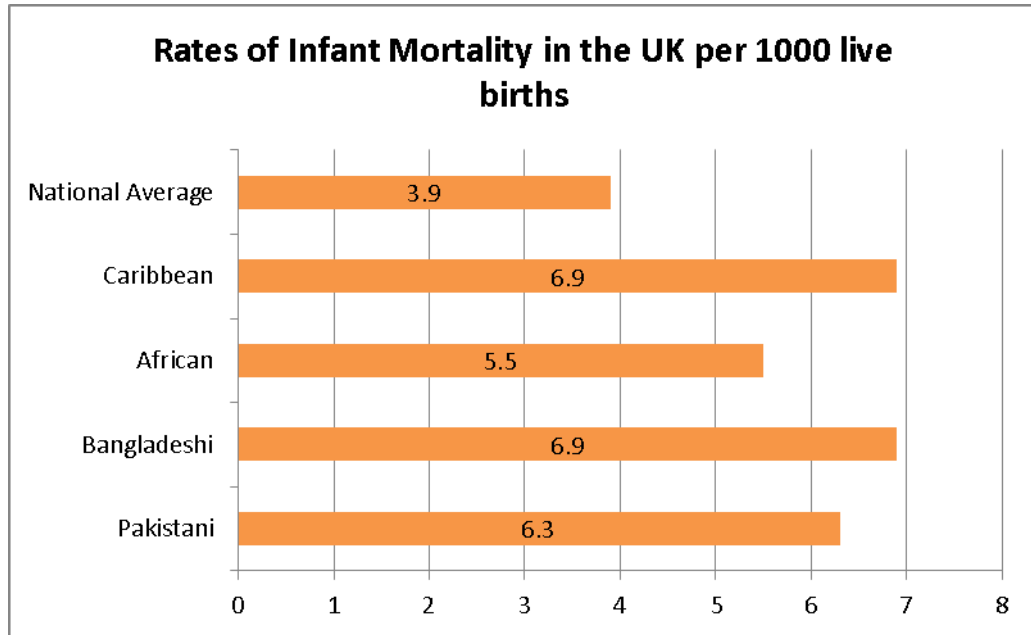
A comprehensive review of relevant literature conducted by Levitas *et al* (2007), defines social exclusion as a:

“complex and multi-dimensional process. It involves the lack or denial of resources, rights, goods, and services, and the inability to participate in the normal relationships and activities, available to the majority of people in a society, whether in economic, social, cultural or political arenas” (Levitas et al., 2007, p. 9)

As a result social exclusion can have profound effects on the quality of life of people who are affected (Kabeer, 2000) including decreased life expectancy and increased morbidity. The concept applies to people experiencing poverty, unemployment, restricted access to services, discrimination and lack of social participation (Levitas et al., 2007). Generally Black and Asian women are presumed to be socially excluded, by virtue of being more likely to be economically disadvantaged, poor, female and members of a disenfranchised racial, ethnic or religious group (Braveman & Gruskin, 2003). Tackling social exclusion and disadvantage have been recommended as key policy targets (DoH, 2007; Marmot et al., 2010).

Although instances of infant mortality occur in every population the highest rates occur in women of Pakistani, West African, Caribbean and more recently Bangladeshi origin (ONS, 2014b). In 2015 the MBRRACE-UK report (Manktelow et al., 2015) highlighted worrying variations in baby deaths across the UK. The report found that Black and Asian mothers are at a 50% increased risk of infant loss (Manktelow et al., 2015).

Figure 1: Rates of Infant Mortality in the UK



Higher child morbidity rates among these groups of women have also been reported, as well as perinatal, neonatal and post neonatal mortality (Andrews & Jewson, 1993). Tackling this health inequality and its implications for infants resulted in the setup of an External Working Group by the DoH to address the issues around maternity services for disadvantaged women (DoH, 2007). The Infant Mortality National Support Team (IMNST) was commissioned and some of its key findings around disadvantaged groups was the need to improve access to antenatal care, improve communication and staff training (DoH, 2010).

Table 1 highlights some of the factors that are known to increase the risk of infant mortality. Bradford District Infant Mortality Commission (BDIMC) conducted a Population Attributable Risk Fraction (PARF) Analysis on the factors described in Table 1 and found that up to 57% of Pakistani infant deaths could be prevented if deprivation was eliminated (BDIMC, 2006).

Table 1: Factors associated with Infant Mortality

Factors associated with multiple deprivation and infant Mortality				
Lifestyle	Smoking	Alcohol & substance misuse	Inadequate or unbalanced diet	
Maternal/Paternal characteristics	Age (either under the age of 18 or over 35)	First baby	Mental & physical health of mother	Inherited or genetic conditions
Access to & quality of maternal care	Access to pre-conceptual health education	Access to antenatal care	Experience of maternity care	Access to post-neonatal care
Environment	Poverty & its consequential living conditions	Overcrowded housing conditions		

The literature suggests that the differences in infant mortality rates can be understood as individual/lifestyle factors or structural/systemic factors whereas the DoH has suggested that it may be an interplay of multiple factors (DoH, 2010). Therefore the following sections will discuss both individual/lifestyle factors and structural/systemic factors.

Infant Mortality and Individual Risk Factors

A number of factors have been identified as increasing the risk of infant mortality, with some of these factors connected to the mothers own health and lifestyle. A higher prevalence of obstetric complications, immaturity related conditions (babies born less than 37 weeks gestation) and congenital anomalies amongst babies born to Pakistani, African and Caribbean mothers has been suggested as the main cause of infant death in these groups (DoH, 2007). Particularly in Pakistani communities consanguinity has been associated with increased prevalence of congenital anomalies in babies (BDIMC, 2006; Parslow et al., 2009). Sheridan and colleagues (2013) have reported that a consanguineous marriage can increase the risk of a congenital anomaly from 3% to 6%. A consanguineous marriage is usually defined as a marriage between two people who are either second or first generation cousins (Hamamy et al., 2011). Kinship patterns based on consanguineous marriages are common in many parts of the world such as Africa, Middle East and Asia (Ahmad, 1994).

Sheridan and colleagues (2013) investigated congenital anomalies in a multi-ethnic birth cohort. They found that 31% of all anomalies in children of Pakistani origin could be attributed to consanguinity. However it was unclear what the nature of these anomalies was and whether they were life-limiting. In addition the study also noted a similar increase in risk for mothers of White British origin who were older than 34 years. Another study by Bunday and colleagues (1991) found that life-limiting congenital anomalies occurred in 1 out of 100 Pakistani babies, accounting for half of the perinatal mortality in this group. The remainder of the excess perinatal mortalities they attributed to other socio-economic and systemic factors, which they suggested are amenable to preventative measures such as the referral of Pakistani women to appropriate pre-maternity care services and clinics. However, most babies born to consanguineous parents are unaffected. For example in the Bunday study only 39 out of 1614 babies born to consanguineous parents had lethal congenital anomalies. Furthermore the association is often confounded by economic and social disadvantage (Bunday et al., 1991; DoH, 2010), such as access to healthcare, maternal education and poverty. In addition Kurinczuk and colleagues (2010) emphasised that consanguinity as a risk factor for congenital anomalies is complex and that studies in the past often failed to take account of socio-economic circumstances and other important confounding variables. Furthermore Ahmad (1994) highlights some of the methodological issues in research on consanguinity and congenital anomalies. In one study, out of 100 randomly selected maternity records of Pakistani women only 59 contained information on consanguinity and a further 16 contained errors in recording of consanguinity (Darr & Modell, 1988). More importantly we know little about how consanguinity is determined in clinical settings, who asks the questions, how are they asked, how acceptable are they to families and how accurate the answers are (Ahmad, 1994).

Many other factors have been identified to increase the risk of congenital anomalies apart from consanguinity, such as mother's age at birth (Jolly, Sebire, Harris, Robinson, & Regan, 2000), obesity (Stothard, Tennant, Bell, & Rankin, 2009), diabetes (Macintosh et al., 2006), alcohol consumption (Martínez-Frías, Bermejo, Rodríguez-Pinilla, & Frías, 2004) and exposure to hazardous waste (Vrijheid et al., 2002). Particularly for maternal age, it has been reported that the risk of chromosomal abnormalities increases by 4-10% in mothers aged over 35 (Cleary-Goldman et al., 2005; Smith, Budd, Field, & Draper, 2011). Furthermore for diabetes and obesity there is evidence for a two-fold increase in the risk of congenital anomalies (Kurinczuk et al., 2010).

Data from the ONS suggests that there is a correlation between the age of the mother at the time of giving birth and unexplained infant deaths. The rate of unexplained infant death was 1.06 deaths per 1,000 live births for mothers aged under 20, which fell to 0.17 for mothers aged

over 35 (ONS, 2012b). Some have argued that the higher rate of unexplained infant death in young mothers may be linked to maternal smoking, as one of the key risks of unexplained infant deaths is maternal smoking during pregnancy (MacDorman, Cnattingius, Hoffman, Kramer, & Haglund, 1997; Mitchell et al., 1993). Interestingly, unexplained infant deaths are higher in mothers born in England and Wales compared to mothers born outside of the UK (ONS, 2014c).

Infant Mortality and Systemic Factors

Looking at individual risk factors in relation to birth outcomes usually provides an incomplete picture, because many researchers have suggested that systemic and environmental factors play a crucial role in birth outcomes (BDIMC, 2006; DoH, 2007; Salway et al., 2010). Therefore a critical consideration of social and health service related factors is essential for a fuller understanding. For example African and Pakistani women have been reported to defer access to antenatal care until later on in their pregnancy (Daniels, Noe, & Mayberry, 2006; Peacock et al., 2001; Rowe & Garcia, 2003). Muslim women, particularly those of Pakistani, Bangladeshi and Somali origin have reported feelings of ambivalence towards government regulated healthcare and often opt for advice from community elders for example their family members (Dartnall, Ganguly, & Batterham, 2005). In addition some disadvantaged women find it difficult to attend antenatal and maternity clinics due to financial strain, whereas others were under the impression that they would have to pay for them (Dartnall et al., 2005). All these factors have been reported to place these women at higher risk of infant mortality (Downe et al., 2009). This is because there are two main points of intervention when looking to reduce infant mortality: uptake of screening and access to antenatal treatment (Kurinczuk et al., 2010). The World Health Organisation (WHO) identified antenatal care and treatment as an essential proponent of safe motherhood (WHO, 1994) as it provides women with advice and guidance, psychosocial support, antibiotic treatments, screening for infections, monitoring and as a consequence recognition of early warning signs (Bergsjø, 2000).

Some of the key strategies recommended by the DoH to reduce the risk of infant mortality include addressing environmental stressors, improving maternity services and increasing social support for women at risk (DoH, 2007). This is because research suggests that the quality and type of support that women receive during maternity significantly affects their health outcomes (Austerberry, Wiggins, Rosato, Sawtell, & Oliver, 2007; Oakley, Hickey, Rajan, & Rigby, 1996). In addition being '*well connected*' to services and people gives access to material and informational resources that can improve health during pregnancy (Gayen & Raeside, 2007). A woman who is '*well connected*' is highly interconnected and centrally

located within her social network for example to friends, family, community and professionals (Gayen & Raeside, 2007). As a result of the recommendation to address social support from the DoH (2007) it seems relevant to explore access to and experiences of maternity services among the general population compared to minority women.

Maternity Services

There has been growing public concern in relation to the delivery of safe maternity care since 2006. The Royal College of Midwives has recently described the current situation in maternity services as ‘*unsafe*’ and ‘*in crisis*’ (RCM, 2012). Latest figures from the National Audit Office (NAO) highlighted that maternity services were spending an average of more than £700 on negligence claims for every birth (NAO, 2013). It also found that in England one in every 133 babies was stillborn or died within a week of birth (NAO, 2013). The current pressure on maternity services across the UK was outlined in a recent report (RCM, 2012), which identified increasing birth-rates. The ‘*baby boom*’ in England and Wales on top of the pre-existing understaffing has led to a chronic shortage of midwives (McInnes & Mc Intosh, 2012).

In relation to this issue the Kings Fund launched an independent inquiry into the safety of maternity services (O'Neill et al., 2008). The inquiry investigated healthcare professionals’ views on the safety of maternity services (Smith, Dixon, & Page, 2009; Thomas & Dixon, 2012). Overall 591 healthcare professionals working in or with maternity services completed a short questionnaire on aspects of maternity care they felt were less safe and ways to improve safety in maternity services. In this group, 80% were midwives and the rest were obstetricians, neonatal nurses, paediatricians and GP’s. The results highlighted a number of problems faced by maternity services such as:

- the increasing medical and social complexity of the pregnant population;
- low staffing levels;
- low staff morale;
- inadequate training;
- poor management;
- lack of resources.

Healthcare professionals acknowledged that more high-risk women with complex social and medical needs were accessing services, yet they did not have adequate training or knowledge to work with these women. Staff shortages also meant that midwives were not able to provide one to one support that might be needed for high risk women in labour. This was connected to low staff morale and healthcare professionals described a “*vicious cycle*” that led

to over-tiredness and burnout. The inquiry also identified a number of recommendations to improve safety in maternity services such as more staff, improved training, more one-to-one care and learning from mistakes. Interestingly, culturally sensitive practice or training was not suggested as a key recommendation for delivery of maternity services.

General Experiences of Maternity Services

Considering the current situation in maternity services, it may be helpful to explore the experiences of all mothers who are accessing this service to gain a fuller picture. A number of maternity services satisfaction surveys have been conducted (Dowswell, Renfrew, Gregson, & Hewison, 2001; Garcia, Redshaw, Fitzsimons, & Keene, 1998; Hildingsson & Thomas, 2007; Hundley et al., 2000; Redshaw & Heikkila, 2010; Redshaw & Henderson, 2015). In 2015 the National Perinatal Epidemiology Unit reported findings from their fourth national survey of women's experiences of maternity care in England and Wales (Redshaw & Henderson, 2015). 4,571 women who gave birth in January 2014 completed a questionnaire on their maternity experience. However, women whose babies had died and mothers aged less than 16 years of age were excluded from the study. Women who responded to the questionnaire were more likely to be older, married, to be living in the least deprived area and to have been born in the UK. A total of 16% of the respondents came from BME groups and 24% had been born outside the UK. Results on patterns of care found that nearly all the women received full antenatal care; only 1% reported that they had not. During pregnancy 68% of the women reported that they had a 'Named Midwife' including their contact details. However women from BME groups were less likely to report this.

Women were also asked to evaluate their maternity care and the results showed that 90% of the women strongly agreed that staff "*talked to them in a way they could understand*" and that they were "*treated with respect and kindness*" (Redshaw & Henderson, 2015, p. 39). Interestingly women were more critical of their postnatal care than of other phases of maternity care. Only 68% of the women felt that they were listened to during their postnatal care.

However, though the majority of women were satisfied with their maternity care (88%) the survey found significant differences between different groups of women. BME women reported poorer staff communication and feelings of not being treated with respect and were less likely to be offered antenatal classes. Their knowledge of choices around maternity care was also limited. Women born outside the UK were less likely to be offered antenatal education classes and less likely to feel involved in decision making. The study found no significant difference between experiences of maternity care and those with fewer years of full-time education or living in a deprived area.

The findings from this study are not dissimilar to those reported in previous national surveys (Garcia et al., 1998; Redshaw & Heikkila, 2010; Redshaw, Rowe, Hockley, & Brocklehurst, 2006). In addition in 2014 Redshaw and colleagues published another report looking at the experiences of parents following stillbirth or the death of their baby after birth (Redshaw, Rowe, & Henderson, 2014). A total of 248 women whose baby died after birth completed the survey, 20% of these were from a BME background. The majority of the women were positive about their care during pregnancy; only 1 in 4 reported not being listened to by professionals. Three quarters of these women felt that midwives communicated with them well during labour and birth and 58% reported having confidence in professionals. Only 13% reported feeling either a lack of confidence or none at all. After the death of their baby the majority of the women reported not being left alone at a time when they felt worried, only 16% reported that they were left alone. Following hospital discharge three quarters of women had the name and contact details of a midwife and were visited by their midwife. Only a small proportion (7%) reported not being visited by a midwife. Overall women reported being satisfied with the care in the Neonatal Unit and during labour and birth. Postnatal care seemed to be an area with which women were most dissatisfied.

In conclusion, generally the studies highlighted positive aspects of maternity care with some room for improvement in terms of continuity of care and neonatal care. However there are a number of limitations, firstly the majority of the sample had normal deliveries with only 9% of the sample reporting any complications. Therefore the studies did to an extent shed some light on the maternity care experiences of women who had complications; however they were not able to investigate maternity care experiences of women who experience infant mortality from diverse backgrounds. This is a general flaw of satisfaction surveys as they fail to capture the experience of subgroups (Teijlingen, Hundley, Rennie, Graham, & Fitzmaurice, 2003).

Gold (2007) conducted a systematic review of parents' experiences of health services, particularly maternity services following an infant death. The Review included sixty-one studies including more than 6000 parents over a 40 year period from 1966 to mid-2006. The results found that generally nurses were viewed as more emotionally supportive than doctors and they received the highest satisfaction ratings of all providers. Some studies did identify negative interactions between parents and nurses, however the majority were positive. Parents valued emotional support, attention to the mother and baby as well as grief education and counselling. However, though the results were mostly positive some dissatisfaction and distressing behaviours were also identified such as avoidance, insensitivity and poor staff communication. Dissatisfaction was only reported at times when staff were unaware of the loss and therefore made an insensitive comment about the baby. However the majority of the studies in this review

were based in the USA and were with predominantly white parents. Furthermore the review included not only infant mortality but other losses such as stillbirth and foetal death, which could have resulted in very different experiences with health care providers. Lastly the review was conducted over a 40 year period and therefore changes in the delivery of maternity services cannot be accounted for.

BME Mothers' experience of Maternity Services

More than a third of all births in the UK are to mothers born abroad and in some areas in the UK more than 50% of the babies born are to Pakistani mothers (Troman, Natamba, & Jefferies, 2008). This is particularly relevant considering that only 11.8% of the population in the UK is from a non-white background (ONS, 2012a), yet BME mothers account for 33% of births. In relation to this it has been suggested that there may be a '*false sense of security*' (Lang, Edwards, & Benzies, 2005) amongst health care providers around whether they are providing appropriate care for BME mothers. It has been suggested that the behaviour of health care professionals can contribute to health care inequality especially in relation to access to services and provision of appropriate care (Puthussery et al., 2008).

Studies conducted in the UK and Europe which have looked at BME mothers experiences of maternity services have found that communication and language, support, control, stereotyping and racism are important issues for BME women (Barj, 1995; Bowler, 1993; Ellis, 2000). Women from minority ethnic backgrounds often report difficult maternity experiences, connected to their position as non-English speaking mothers (Barj, 1995; Bowes & Domokos, 2003; Bulman & McCourt, 2002; Woollett, Dosanjh-matwala, & Hadlow, 1991). Bulman and McCourt (2002) interviewed twelve Somali women using an interpreter and found that the language barrier was the most important problem faced by these women during their contact with maternity services. The study found that language and interpreting services were rarely offered and suggested that this had major implications for care, such as whether pain control was discussed with mothers or not. In relation to this some have argued that health care policies and practice in the UK assume that all service users are white and English speaking (Rudat, Roberts, & Chowdhury, 1996). In addition in Norway it has been reported that Pakistani women are three times less likely to receive adequate analgesia in labour, suggesting that systematic discrimination may exist in maternity services (Vangen, Stoltenberg, & Schei, 1996). As a result of the growing pressure on maternity services from policy makers (DoH, 1998; MCHRC, 1998) to tackle racism in maternity services the Royal College of Midwives has published a position paper highlighting a need for institutional racism and the care ethnic minority women receive to be addressed in maternity services (RCM, 2000).

Bowler (1993) collected observational data and conducted formal interviews with 25 midwives in a British maternity hospital. The results highlighted damaging stereotypes and attitudes held by some of the midwives in her study, which she suggested had massive implications for the delivery of care to BME mothers; attitudes such as BME women have a tendency to “*make a fuss about nothing*” and lack “*normal maternal instinct*” (Bowler, 1993, p. 157). Bowler (1993) suggests that these stereotypes reflect and reinforce the view amongst some midwives that Asian women are all the same, but not like the rest of ‘us’. In addition Bowler (1993) also purported that this would then affect the judgements some midwives made on the type of care needed, wanted and deserved by BME mothers. Interestingly the majority of the data came from natural interviews and unsolicited accounts recorded during observations in between antenatal clinic and labour.

In a more recent study Jomeen and Redshaw (2013) conducted a UK wide survey using NHS data from 2006 to investigate BME mother’s experiences of maternity care. The study conducted secondary analysis on questionnaires returned by 368 BME women of which 219 had open text. The study highlighted a number of key themes in relation to BME mothers experiences of maternity services some of which were attitudes and communication, choices were denied, the impact of stereotyping, the importance of ethnicity and culture and the need to feel that the hospital is a “*safe place*” (Jomeen & Redshaw, 2013, p. 288). The study also found that BME mothers described staff attitudes in largely negative terms; they spoke about feeling disappointed about their treatment, issues in relation to communication and information giving and a lack of respect, sensitivity and individually tailored care. One UK born Pakistani woman powerfully described her experience:

“Some midwives do not make even eye to eye contact. All visits are “routine” without information given I am sad to say there is not enough care and attention from doctors and midwives as there should be. At antenatal appointments it is simply routine with no interest in particular given to an individual expectant mother, no helpful or interesting advice and facts are given, nor any sort of civil conversation...When I reached [hospital] I felt interrogated by the midwife as if I was a criminal and not a patient! ‘can you tell me what happened?’ - to fill in her notes on her clipboard seemed more important.” (Jomeen & Redshaw, 2013, p. 288)

Other research has also reported similar findings (Cross-Sudworth, Williams, & Herron-Marx, 2011). However this may also suggest that nurses and midwives need to be supported, for example through provision of further training to change their attitudes and enhance their confidence in working with BME mothers.

Another recent study by Mir and colleagues (Mir, Spicer, & HOPE, 2013b) “investigated the nature of social networks for maternal and child health for women from diverse backgrounds” (2013b, p. 1). Researchers interviewed 23 women from African and Pakistani backgrounds as well as mainly White British teenage mothers who had experienced an infant death and 26 women from a range of ethnic backgrounds who had felt well supported during pregnancy and had a child over one year of age. The study explored “links between women and contacts in their personal networks that provided support during pregnancy and after the birth” of the infant. The study highlighted some key findings around perception and management of risk, sources and levels of support and relationships within women’s networks. In terms of perception and management of risk, bereaved women and their families often had poor knowledge of pregnancy complications and often delayed reporting warning signs. Though professionals were good at organising extra appointments, a number of ethnic minority bereaved women complained that their concerns were not taken seriously, particularly in relation to admissions. There was also considerable divergence between the experiences bereaved women described and professionals’ descriptions of risk factors. The study found that some professionals focussed heavily on issues external to maternity services such as deprivation and genetic causes. Furthermore the routine lack of language support could distress mothers for example when they had to interpret for their husbands whilst being given news of their infant’s death. One Pakistani woman called Ansa described what happened to her: “*There was no interpreter offered to us so I had to translate what was happening when I was trying to come to terms with it myself*” (Mir, Spicer, & HOPE, 2013a).

In terms of sources and levels of support, the study identified more than 80 potential sources of support in total. However the study found that non-bereaved women were able to name more sources of support in their contacts compared to bereaved women. Non-bereaved women were also more likely to rate GP’s, midwives and health visitors more highly on average than bereaved women in terms of level of support and whether they felt their health and wellbeing was considered. Pakistani women were found to be less likely to access antenatal groups and those who did reported that these groups “*did not prepare them to recognise warning signs of complications*” (Mir et al., 2013b, p. 4). The study also highlighted a lack of representation of minority women in decision-making bodies. In summary the study highlighted the importance of gaining feedback from bereaved women on their experiences of maternity care, the employment of more ethnic minority staff in maternity services and the need to focus on multifactorial explanations for infant mortality in line with evidence, rather than just genetic factors. The study also illustrated some high quality programmes of support such as Specialist Teenage Pregnancy Midwives and the National Family Nurse Partnership for teenage mothers

and suggested there was considerable potential to transfer aspects of this model to other high risk women such as African and Pakistani mothers (Mir et al., 2013b).

Bereavement and Grief

Grief is a normal process that occurs following the loss of a loved one and is naturally marked by emotional distress following the loss. Earlier psychological theories of grief most commonly described it as a process involving dynamic progression through phases (Bowlby, 1980; Kubler-Ross, 1969; Kubler-Ross & Kessler, 2005).

Kubler-Ross (1969) suggested five stages of grief as typical responses to dying; these stages are emotional states that the dying patient, as well as those who lose a loved one (Kubler-Ross & Kessler, 2005), go through before finally accepting death. This work laid the foundations for bereavement theory and grief work. The five stages described in the theory are: denial, anger, bargaining, depression and acceptance. However the five stage model has since been criticised for a number of reasons. Firstly the work of Kubler-Ross (1969) was based entirely on interviews with terminally ill patients and many have questioned whether the five stages are applicable in other situations e.g. infant mortality, sudden death etc. (Kirkley-Best & Kellner, 1982; Smith & Borgers, 1988). Furthermore she did not interview those who were close to patients regarding their reactions to the loss and therefore transferability of the model is questionable. In addition Kubler-Ross (1969) did not take into account the resources, pressures and characteristics of the immediate environment (Kastenbaum, 2004). Kastenbaum and Aisenberg (1972) argued that a patient's environment can have a foremost effect on their attitude towards death, as a patient in an encouraging and compassionate environment is likely to display distinct responses to dying compared to a patient in a pessimistic and obstructive environment. It is ironic that Kubler-Ross (1969) dismissed the effects of the environment on the types of responses portrayed by the patient, as she was initially enticed into researching the area after observing the environment around a terminally ill patient (Blaylock, 2005). She exposed hospitals as depersonalised surroundings in which patients were regarded and dealt with like things, she said "*He may cry for rest, peace and dignity, but he will get infusions, transfusions, a heart machine or tracheostomy if necessary.*" (Kubler-Ross, 1969, p. 8).

Some have suggested that infant mortality and grief reactions may be best understood when viewed through the framework of attachment theory (Robinson, Baker, & Nackerud, 1999). John Bowlby was the first to revolutionise thinking around a child's tie to the mother and its disruption through separation, deprivation and bereavement (Bowlby, 1969). He highlighted the pathogenic potential of loss through detailed case studies on maladjusted children and linked it to their histories of maternal deprivation and separation (Bowlby, 1940, 1944). Robertson and

Bowlby (1952) identified three phases of separation response: protest (related to separation anxiety), despair (related to grief and mourning) and denial or detachment (related to defence mechanisms). John Bowlby and Mary Ainsworth (1991) then developed attachment theory and the influence of mother-infant interactions on the development of the child's personality. However John Bowlby and Mary Ainsworth's work mainly focussed on the effects of maternal deprivation and loss on the development of the child, less is known of the effects on the mother. As a result Maternal Fetal Attachment is a relatively new concept and has not been well studied or defined (Salisbury, Law, LaGasse, & Lester, 2003).

Cognitive processing models have also been developed to understand the process that people go through to cope with bereavement such as the Dual Process Model (Stroebe & Schut, 1999). This model suggests that people engage in both confrontation and avoidance of their grief at different stages in their bereavement (Stroebe & Schut, 2001). In this sense the individuals oscillates between loss-orientated coping where they focus on their grief and restoration-orientated coping where they may engage in other tasks to avoid their grief. However this model too proposes that there is an end point to grief and that grievers "*come to terms with the loss of a loved one*" (Stroebe & Schut, 2010, p. 277). Furthermore models of bereavement and grief described above all draw on ideas of linearity and sequential time. More recently it has been suggested that bereavement fractures the sequential experience of time and that any model of grief that relies on linearity is inappropriate (Small, 2009).

In addition there has been a move away from labelling grief as either normal or abnormal (Archer, 1999). New theoretical perspectives reject the concept of breaking bonds or '*letting go*' as a means of resolving grief. Instead based on actual studies of bereaved parents, these new models emphasize the concept of '*continuing bonds*' (Klass et al., 2014). These new models are more complex and individually based understandings of the experience of grief and incorporate ideas around resilience, coping resources, the importance of talking about the loss and maintaining connections (Mancini & Bonanno, 2006). Klass and colleagues (2014) have highlighted that the concept of continuing bonds has many implications for therapeutic interventions and service delivery, particularly that interventions need to be customised to meet the individual needs of the bereaved as well as serve to promote healthy continuing bonds. Similarly Neimeyer and colleagues have highlighted the importance of meaning-making and narrative in re-constructing grief (Neimeyer, Burke, Mackay, & van Dyke Stringer, 2010). Neimeyer suggests that people need to be supported in integrating their grief and loss in to the story of their lives, rather than be expected to '*move on*', he suggests that loss shapes their view of the world and their sense of who they are. He has also suggested that Narrative Therapy

would be a useful and less stigmatising intervention for grief and bereavement (Neimeyer, 1999).

Psychological reactions to the loss of an infant

It is now generally accepted that following the death of a young infant parents can suffer from prolonged or complicated bereavement (Boyle, 1997; Vance, Boyle, Najman, & Thearle, 2002). Parents have reported physical symptoms, depression, anxiety and disruption to normal functioning which is similar to the responses described by others following the loss of an older child or a spouse (Murray et al., 2000).

Difficulties in mourning can arise when mothers perceive limited social support (Dyregrov & Matthiesen, 1987; Elder & Laurence, 1991), have an ambivalent relationship with the infant (Lasker & Toedter, 1991), there are traumatic circumstances around the death (Murray & Callan, 1988), there have been difficulties in coping with crisis in the past (Lasker & Toedter, 1991), other life stresses were present during the time of the loss (Murray et al., 2000) and there are problematic relationships in the nuclear family (Black, 1992; Boyle, 1997).

Some of the key factors linked to psychological sequelae following loss of an infant are social support and talking (Stroebe, Schut, & Stroebe, 2005; Thuen, 1997). Lepore, Cohen Silver, Wortman and Waymerit (1996) examined how social constraints on talking influence the psychological adjustment of parents following the unexpected loss of an infant. They interviewed 98 bereaved mothers at 3 weeks, 3 months and 18 months after the death of the infant. The interview explored the desired and actual amount of talking to their social network about the loss of their infant. They also administered the SCL-R 90 Depressive Symptoms Scale (Derogatis, 1996), an Intrusive Thoughts Scale and a Social Constraints Scale (Lepore et al., 1996). They suggested that infant mortality was linked to mothers' depressive symptoms and intrusive thoughts regarding the infant following the death. They also found that social constraints on talking about the death of the infant were linked to increased depressive symptoms. This highlights that social constraints inhibit mothers from talking about the trauma, which in turn may interfere with their ability to process the loss and emotionally adapt to it (Clark, 1993). Therefore bereaved mothers can feel supported when they can see that others understand what their loss means and can accept the powerful feelings that accompany that loss (Leon, 1992).

As a result many have suggested the need to identify mothers and families at risk of developing complex grief reactions following infant mortality to reduce the risk of long-term mental or physical health problems (Murray et al., 2000). Families at higher risk of developing complicated grief are those with limited social support, families that have had experience of

other losses (Murray et al., 2000), traumatic circumstances around the child's death and problems in the family. Early identification and intervention would also reduce the costs of hospitalisation and family disruption (Harper & Wisian, 1994).

Minority ethnic women, loss and bereavement

Some authors have suggested that the reactions to the death of an infant may be culturally grounded (York & Stichler, 1985). Women and families are likely to respond to the death of an infant by drawing on cultural perceptions regarding the tragedy of death, attitudes towards the expression of grief, religious beliefs around life and death as well as the availability of social networks and support (Kalish & Reynolds, 1976; York & Stichler, 1985). However a detailed search of the main literature databases (Appendix I) yielded only a handful of studies which looked at the experience of infant mortality in minority women.

Boone (1985) conducted intensive, exploratory interviews with Black American women who had suffered an infant death within one year of delivery. The women expressed “*bitterness and resentment*” at the lack of social support available to them from family (Boone, 1985, p. 1001) and fear of doctors and nurses represented the single most important factor in their perception of health care providers as inaccessible. The study suggested Black American women felt powerless, hopeless and that life is meaningless, following the loss of an infant. Boone (1985) suggested that these feelings of powerlessness stemmed from their position in the American social system and led to a fatalistic outlook on life. Some of the recommendations following this were the development of programs such as counselling, self-help strategies and mutual support groups to tackle social alienation and psychological distress of inner city black women during and after pregnancy.

However experiences of infant mortality amongst Pakistani women remain under-researched. The majority of research which has explored the voices of women following the loss of an infant has concentrated on White women (Black, 1992; Côté-Arsenault & Morrison-Beedy, 2001; McCreight, 2008). In addition studies which have attempted to explore the bereavement experiences of socially disadvantaged women have been conducted in the USA with African American women only (Boone, 1985; Van, 2001). Currently, limited comparable literature exists on the experiences of infant loss among either Pakistani women in the UK or in Pakistan (Appendix I).

Research Questions

It has been suggested that the topic of infant mortality should be explored from the viewpoint of these marginalised women, and that research which does this would be of clinical relevance (Downe et al., 2009). Lepore and colleagues (1996) suggested that future research on

infant mortality should give high-risk women an opportunity to talk about their experiences of the death, as a way to understand their lived experience. It has also been suggested that the voices and experiences of minority women should influence the design and delivery of services and that this is one way to raise their “*muted voices*” (Bowes & Domokos, 1996, p. 45). With this in mind this research project aims to explore the perspectives and experiences of bereaved Pakistani women following infant mortality. The research aims and questions are:

- ~ What are the bereavement experiences of Pakistani women in relation to infant mortality?
- ~ How do these women make sense of their experience following the loss?
- ~ Do the narratives of these women suggest ways in which services might develop to meet their needs?

METHOD AND METHODOLOGY

Context and Design

Due to the exploratory nature of the research question and the importance of gaining a deeper understanding and insight into the experiences of Pakistani women who have lost a baby, a qualitative design was deemed appropriate. A qualitative design also allows the research to give a voice to these marginalised women. There were a number of reasons for focusing on Pakistani women, such as the fact that these women are under-represented in research on experiences of infant mortality despite experiencing higher rates. In addition recruitment of Pakistani women would have been difficult, therefore a link with a bigger study on Social Networks and Infant Mortality funded by the Economic and Social Research Council (ESRC) (Mir et al., 2013b) facilitated access and recruitment of Pakistani women. Pakistani women comprised a large proportion of their sample due to the demographics of the research sites.

Qualitative Methodological Approach

Narrative Inquiry

BME women have been classed as a marginalised and oppressed minority (Ali, Kalra, & Sayyid, 2008; Jordan-Zachery, 2007), and it is their stories that provide significant insight into the experience of infant mortality. Hesse-Biber, Leavy and Yaiser (2004) suggest that:

“Starting research from the standpoint of the oppressed is valid because it is often the lives and experiences of oppressed people that provide significant insight and perspective. Complex human relations can become visible when research is started at the bottom of the social hierarchy” (2004, p. 16)

Bearing in mind that these women are often under-represented in decision-making bodies (Mir et al., 2013b), narrative inquiry is a method which allows for these women’s narratives and experiences to be privileged and heard (Liamputtong, 2007). The aim of narrative interviews is to unearth the meanings inherent in the narratives obtained, remaining faithful to the multiple intentions of the narrator, without constructing them differently (Tappan, 1997).

The project used a specific form of narrative interviewing, namely the Biographic Narrative Interview Method (BNIM). Biographic Narrative Interviewing was first developed as an “*interview design that focuses on the elicitation and provocation of story-telling*” (Wengraf, 2001, p. 111). The format of the Biographic Narrative Interview gives women considerable control over the direction of the interview, which should therefore allow them to speak freely and openly (England, 1994). Furthermore the Biographic Narrative Interview allows the

researcher to work from a “*power-sensitive*” (Hesse-Biber & Leavy, 2010, p. 199) perspective, therefore reducing the imbalance in power between researcher and the participants. This method allows researchers to pay attention to the needs of “*those who have little or no societal voice*” (Rubin & Rubin, 2011, p. 36).

Whilst the participant’s role is to tell the story of their experience of the event, the researcher’s task is hermeneutic, reconstruction and interpretation (Josselson, 2004). Data analysis relies on hermeneutics, a disciplined and skilled task of moving from text to meaning (Ricoeur, 1991). It has been suggested that taking a feminist or social critical stance allows researchers to accommodate and capture the perspectives, beliefs and experiences of minority women without distortion or misrepresentation (Malik, 2008).

The “perspective”

When conducting research Carter and Little (2007) have suggested that the ontological, epistemological and methodological assumptions underpinning the inquiry should be outlined and made visible. In this case the research adopted explicitly a feminist and social critical framework. Feminist and social critical frameworks are not a method, but rather a “*perspective*” (Reinharz, Davidman, & Conochie, 1992, p. 241). Research conducted with this “*perspective*” acknowledges that reality is influenced by social, political, cultural, economic, ethnic and gender factors (Guba & Lincoln, 1994). In addition knowledge that is constructed in the research process is subjective and transactional, in other words knowledge emerges from a dialogue/interaction with others (Guba & Lincoln, 1994).

Taking this stance is useful as “*groups unequal in power are correspondingly unequal in their ability to make their standpoint known to themselves and others*” (Collins, 1990, p. 26). Women from socially disadvantaged backgrounds often feel that research is further alienating them; in feminist research the concept of alienation is core as it recognises research as alienated knowledge (Morris, 1992). BME feminists argue that modern societies rest on several major systems of oppression, one of them being racial oppression (Collins, 1990). In general, the standpoint of feminist research is that those whom a society oppresses have more potential to see the real oppressive nature of that society than those whom it favours (Harding, 1986).

Minority women can experience multiple layers of social exclusion (Beal, 2008; King, 1988) for a number of reasons, such as in relation to their gendered identity, their ethnic group, their religious identity and their socio-economic status. Therefore taking a feminist and social critical “*perspective*” allowed me to acknowledge the context in which these women’s bereavement takes place.

In this sense the research was orientated towards facilitating empowerment of Pakistani women and potentially supporting social change. From a feminist standpoint it aimed to give a voice to the marginalised (DeVault, 1999) and to construct knowledge which may be of benefit to Pakistani women as well as those working with them.

Alternative Approaches

An alternative qualitative research method that was considered was Interpretative Phenomenological Analysis (IPA). IPA involves two levels of interpretation known as '*the double hermeneutic*': first there is the participant's interpretation of the experiences and second there is the researcher's interpretation of the participant's experiences (Smith, Flowers, & Larkin, 2009). IPA has often been criticised for privileging the researcher's interpretations of the experience during the analysis process over the participants' interpretations (Larkin, Watts, & Clifton, 2006; Pringle, Drummond, McLafferty, & Hendry, 2011). In addition it relies heavily on the use of language and what is said in interviews rather than what remains unsaid (Willig, 2013). Therefore it was deemed that IPA would not be appropriate for the present study as the aim was to privilege women's own standpoint, perspectives and voice rather than the researcher's in making sense of their experience.

Another method that was considered was Grounded Theory (Glaser & Strauss, 1967), a methodology for developing theory through data that is systematically gathered and analysed (Strauss & Corbin, 1994). Theory evolves through continuous interplay between analysis and data collection, a central feature of this analytic approach is "*a general method of constant comparative analysis*" (Glaser & Strauss, 1967, p. vii). As a result Grounded Theory was not deemed an appropriate method of analysis as the aim of the present research was not to develop an explanatory theory. Grounded Theory also suggests that the researcher is independent of the researched, and has minimal influence on the data (Annells, 1996), whereas the present research acknowledges the influence the researcher has on the process and the construction of knowledge.

As with any other paradigmatic position, narrative inquiry is also open to criticism. Similarly to IPA, Narrative Inquiry also has the potential to privilege the researcher's interpretations over the participants'. To avoid this a number of steps were put in place in line with feminist research, such as sharing the interpretations of the narratives with the women to get their agreement/feedback, but also as a quality check. Another legitimate criticism of narrative inquiry is that researchers often "*re-present narratives as if they were authentic*", they can be enticed into believing that in order to represent faithfully another's story, the story needs to be simply reproduced (Trahar, 2009, p. 1). In reality the reproduction will only ever be as the

researcher heard it, therefore I will never know if the stories told would be the same if told to another person or even told at all. A number of quality checks were put in place to avoid biased interpretations, such as checking interpretations with supervisors and participants, as discussed in the later section on Quality Checks. Despite these criticisms and following consideration of alternative approaches, Narrative Inquiry was deemed to be the most appropriate qualitative research method for the present research; particularly because it acknowledged the social, cultural and political influences on the narrator and the narrated.

Data Collection

The main tool of data collection was a Biographic Narrative Interview (Wengraf, 2001), chosen because this has the potential to empower the women to speak from and about their own experiences. The interviews lasted up to 90 minutes and a Biographic Narrative interview schedule (Appendix II) was developed to elicit the women's stories. Brief demographic information was obtained at the start of the interview, such as age, religion, occupation, cause of infant death (Appendix III). This information made it possible to create a holistic narrative portrait of the women interviewed. All interviews were recorded on a dictaphone.

The Biographic Narrative Interview begins with a '*Single QUestion aimed to Induce Narrative*' (SQUIN), a question that allows the participant to tell their story. The SQUIN for this study was as follows:

“As you know I am doing research into the bereavement experience of women who have lost a child. Can you please tell me about your experience of bereavement and any support you received? You can tell your story in any way you feel comfortable, all the events and experiences that were important to you...perhaps beginning with telling me a bit about when problems first started to occur, what happened immediately afterwards and your journey since the death...I will listen first and not interrupt you while you are telling me what happened to you, but I will take some notes so I can ask you questions about it when you have finished”

Once the interviewee has understood the SQUIN and begins to narrate their experience, the interviewer engages in active listening and makes notes of topics raised in the sequence they were raised on a BNIM Pin Sheet (Appendix IV). Topic notes then allow the interviewer to ask the interviewee for further narrative once they have finished answering the SQUIN. Once the interviewee has finished their narrative the interviewer looks at the topics raised by interviewee and turns them into '*Topic QUestions seeking Narratives*' (TQUINs). The latter half of the interview involves asking specific questions about events that the interviewee has already raised

to get further information. The formulation of these TQUINs can be seen in the Interview schedule.

Sampling

The Social Networks & Infant Mortality Study

The current study drew on a sample of bereaved Pakistani women from a pre-existing ESRC study at the University of Leeds. The Social Networks and Infant Mortality study was a multi-site project investigating the nature of social networks for maternal and child health for women from diverse communities in two sites in the North of England (Mir et al., 2013b). The Chief Investigator was Dr Ghazala Mir (also a research supervisor for the current study) at the University of Leeds and the study was funded by the ESRC. The project utilised an empowering model of participatory research and interviewed 23 women from African, Pakistani and teenage backgrounds with experience of infant loss as well as 26 non-bereaved women from a range of backgrounds who felt well supported during pregnancy. The project explored the quality of social networks around bereaved and non-bereaved women. The study inclusion criteria can be found in Appendix V. The Foundation for the Study of Infant Deaths (FSID) recommends that it is appropriate to interview a woman at least 6-12 months after the loss. This guidance was incorporated into a recruitment protocol from the existing study (Mir et al., 2013b) which also drew on the judgement of professionals working most closely with bereaved parents..

The Sample

The research was conducted in the North of England, specifically in Bradford and Leeds. There are a number of reasons why these two sites were chosen; firstly the pre-existing study was conducted at the same sites and secondly a large proportion of the population in Bradford is from a Pakistani background. Furthermore at both sites infant mortality rates have been reported to be higher than the national rate (BDIMC, 2006; Yellin, 2013). The research targeted Pakistani women who had experienced infant mortality; these women represent an often invisible and silent subpopulation (Anthias & Yuval-Davis, 1983; Chantler, 2002).

Seven bereaved Pakistani women were interviewed drawn from the pre-existing study (Mir et al., 2013b). The pre-existing study had 7 Pakistani women that took part in the participatory phase; all 7 women were approached and interviewed for this project. This study used the same inclusion criteria as that study (Appendix V), which was as follows:

- Identifies as a Pakistani;
- Aged 16 or over;
- Experience of infant mortality

- Professional/researcher opinion that the woman will not be overly distressed by inclusion

Though a sample of 6-8 participants is seen as appropriate for Narrative Inquiry in order to yield valid results (Sandelowski, 1995), I interviewed all the bereaved Pakistani women who took part in the participatory phase of the pre-existing study, if they consented. This approach did not restrict the research project to a pre-determined sample size and also allowed me to hear the experiences of as many Pakistani women who were interested in the study.

Details of the women who took part in the study are provided in the results section (Table 3). The women were involved in choosing their own pseudonyms as well as for their babies.

There were many differences and similarities across the sample, for example all of the women were Muslim and Pakistani. Nonetheless it is important to bear in mind that differences may exist even within apparently homogenous groups such as to what extent each woman identifies as a Pakistani and the extent to which religion plays a role in their life. Socioeconomic position and language were also notable differences between the women, for example not all the women spoke English.

The Recruitment Procedure

In terms of the recruitment procedure, there are a number of steps that were taken before consent was obtained. The Social Networks and Infant Mortality project developed two bereavement support groups for women who had experience of losing a baby, named HOPE-Bradford and HOPE-Leeds. These groups consisted of 7 bereaved Pakistani women. I was invited and met the women at one of the sessions in March 2013 at which I first introduced the research project to ascertain whether they would be interested. Following this initial contact I met with the women again in September 2013 at a conference and discussed the study and their thoughts about it. Following this Ghazala Mir contacted the women to enquire whether they were happy to be contacted by me. If the women agreed, then I sent out a letter (Appendix VI) arranging a date and time to meet to discuss the study in detail and if appropriate to take consent. The letter also included a copy of the participant information sheet (Appendix VII). The time and place of the initial meeting was mutually agreed and for all the women it was at their own home. When I met with the women I spent time going through the information sheet, answering any of their questions, and if appropriate sought consent (Appendix VIII). I also tried to make information culturally and linguistically appropriate in relation to the needs of each woman. For instance one woman required information to be provided in Punjabi, I am bilingual

and therefore I was able to meet this need. If necessary I met with the women on more than one occasion before taking consent and undertaking the interview.

There are a number of reasons why the following recruitment procedure was deemed appropriate. This is because ethical considerations were an extremely important part of this research, firstly due to the sensitive nature of the topic and secondly because the women are classed as a vulnerable group (Liamputtong, 2007). Hence to reduce distress I employed a practical, trust building and rapport generating ‘*ethics as process*’ model (Ramcharan & Cutcliffe, 2001), right from the beginning. This allowed me to develop trust at the women’s own pace.

Interviews were arranged within two to four weeks of the initial meeting.

Ethical Considerations

Ethical Approval

The project drew participants from the pre-existing study which had ethical approval from the South Yorkshire Research Ethics Committee. A substantial amendment was requested on this project to incorporate data collection for this project. The project was reviewed by the Committee and obtained a favourable opinion on 3rd October 2013 (Appendix IX).

Consent

The study complied with the British Psychological Society’s guidelines on human research ethics (BPS, 2010). In line with this procedure all women were provided with a detailed information sheet (Appendix VII) at their initial meeting with the Researcher. The Information Sheet included what the research involved, time commitments, confidentiality as well as what will happen with the data. The women were given an opportunity to ask questions and to discuss any other worries at this initial meeting. Information was also provided in a culturally and linguistically appropriate way in order to meet the needs of the women, for example information was translated for women who did not speak English. Following this the women were given a minimum of 48 hours to decide whether they wanted to take part in the research.

At the start of the interview consent was revisited, the women were once again given an opportunity to ask questions and then they were presented with the consent form (Appendix VIII). Two consent forms were signed, one copy for the woman and another for the Researcher. At the end of the interview women were again informed of their right to withdraw. None of the women withdrew their consent to take part in the research.

Topic Sensitivity and Dealing with Distress

The project raised important ethical issues about interviewing women who have experienced the loss of an infant. It was anticipated that some of the women may become distressed during the process of the interview due to the nature of the topic discussed. Therefore a Protocol for dealing with distress developed for the pre-existing study was used in the event that a woman became distressed during the interview. (Appendix X). The escalating support framework for different levels of distress assisted in identifying the form and route for appropriate support if needed. To manage distress during the consent process all women were asked if they had anyone they could go to for support if necessary. This made it possible to identify the women who may not have appropriate support in place and therefore to make recommendations for support. Furthermore at the end of the interview during the debriefing session appropriate sources of professional support were recommended, such as contact details of the UK Stillbirth and Neonatal Death Society and other organisations for support (Appendix XI). The women were also told that they were free to contact either the Researcher or Ghazala Mir if they felt the need to do so.

The impact of hearing women's stories on the researcher was also considered and as a result, there was an opportunity to meet with supervisors before and after an interview if there were any concerns or issues about the interview or that may have come up during the interview. Furthermore additional supervision was also organised with a staff member from the Doctorate in Clinical Psychology Department to discuss personal reactions to the interviews.

Confidentiality

All interview transcripts were anonymised and therefore pseudonyms were used. The women were also informed in the Information Sheet about the people who would have access to the data and will be reading the report. At the start of the interview it was explained to the women that the only caveat to confidentiality would be if any issues around risk were raised during the course of the interview. The only other caveat was the use of anonymised extracts from the interviews in the final write-up or in future publications. The main reason for this was that in cases where the women had unique experiences this could potentially make them identifiable, nonetheless due care was taken to exclude information that could lead to identification.

Involvement Fee

All women who took part in the study were offered a £15 gift voucher as a token of gratitude for giving their time to participate in the research. The voucher was offered at the end

of each interview and all the women accepted this offer. It was also reiterated at this point that the women could withdraw without losing their voucher.

Analysis

In general, narrative analysis looks at the stories people tell and how they are told, which can include form, structure and content (Riessman, 1993). However one main criticism of narrative analysis is the lack of specific guidance around how to go about conducting the analysis or the processes involved (McCance, McKenna, & Boore, 2001). Therefore this research project incorporated Ritchie and Spencer's (2002) Framework Analysis as it provides a more systematic and transparent process of analysis. It is also not wedded to any pre-existing theoretical framework (Ritchie & Spencer, 2002). This allowed us to work with the narratives in a systematic way. Framework Analysis is a method of data analysis rather than a research paradigm such as Narrative Inquiry or Grounded Theory (Ward, Furber, Tierney, & Swallow, 2013). In addition there is evidence that narrative analysis can be successfully incorporated into other forms of analysis (Floersch, Longhofer, Kranke, & Townsend, 2010; Lal, Suto, & Ungar, 2012) and that it has been used in conjunction with Framework Analysis (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Monrouxe & Rees, 2012). Framework Analysis was also developed for social policy research and therefore allows for the transformation of theoretical propositions into potential actionable outcomes (Ritchie & Spencer, 2002), which is particularly important as clinical application is a key part of this research. Finally the analysis also included the development of Narrative Portraits.

Ritchie & Spencer's (2002) Framework Analysis

The recommended process of analysis as outlined by Ritchie and Spencer (2002) can be found below:

Table 2: Stages of Analysis

Step	Title	Description
1	Familiarization	The researcher familiarises themselves with the data by reading and rereading transcripts, listening to the recordings. During this process the researcher becomes aware of the key ideas and recurrent themes and makes a note of them
2	Identifying a Thematic Map	This stage involves recognising the recurring themes or issues in the data set. At this stage the researcher must allow the data to dictate the themes and issues. The key issues, concepts and themes that are expressed by the participants then become the basis of a thematic framework that can be used to code the data. This process usually consists of refining the framework a number of times.

3	Indexing	This stage involves applying the thematic framework to all the data using codes for each theme and subtheme.
4	Charting	This stage involves arranging the coded data into charts of the corresponding themes. The data is lifted from the original transcripts and placed in charts that consist of the headings and subheadings from the thematic framework. This therefore allows you to see what each participant said in relation to each theme, as well as what all the participants said.
5	Mapping & Interpretation	The final stage is mapping an interpretation which involves the analysis of key characteristics as laid out in the charts. The aims of the research project are important at all stages of analysis, but at this stage the researcher is particularly mindful of the aims.

Narrative Portraits

Narrative Portraiture is a relatively new idea in qualitative research and Narrative Inquiry (Gaztambide-Fernández, Cairns, Kawashima, Menna, & VanderDussen, 2011; Smyth & McInerney, 2013). Smyth and McInerney (2013) suggest that Narrative Portraits are inclusive of the lives, perspectives, experiences and viewpoints of the least powerful and should be used with socially disadvantaged groups. Narrative Portraits are known to recreate the “*immediacy and spontaneity of the actual encounter (between the researcher and the participant)*” (Blauner, 1987, p. 5). Narrative Portraits have also been used with Pakistani women in other research on their life experience following traumatic events (Chaudhry, 2004). Therefore to fully understand Pakistani women’s experiences of infant loss, it was necessary to include the context within which their experiences occurred. The Narrative Portraits were constructed in order to contextualise each woman’s experience. However there is a lack of specific guidance on the development of Narrative Portraits, as well as a lack of consistency in how these are constructed within existing studies. Therefore I attempted to achieve consistency between each Portrait by using a standard format for each participant. As a result a Narrative Portrait for women in my sample included (i) the context around the interview, (ii) reflections on the relationship between the researcher and interviewee from the researcher’s perspective and (iii) a summary of the woman’s narrative, particularly focusing on the key themes as emerging from steps 1-4 in Table 2. They were then refined and developed through an iterative process. All seven portraits were reviewed by both supervisors. In addition all the women were given copies of the Narrative Portraits and offered an opportunity to comment on them (Appendix XII). Any changes that they recommended were accommodated.

The Process of Analysis

I now document the stages of analysis I went through for both the Narrative Portraits that were developed for each woman and the group Framework Analysis. I have also developed

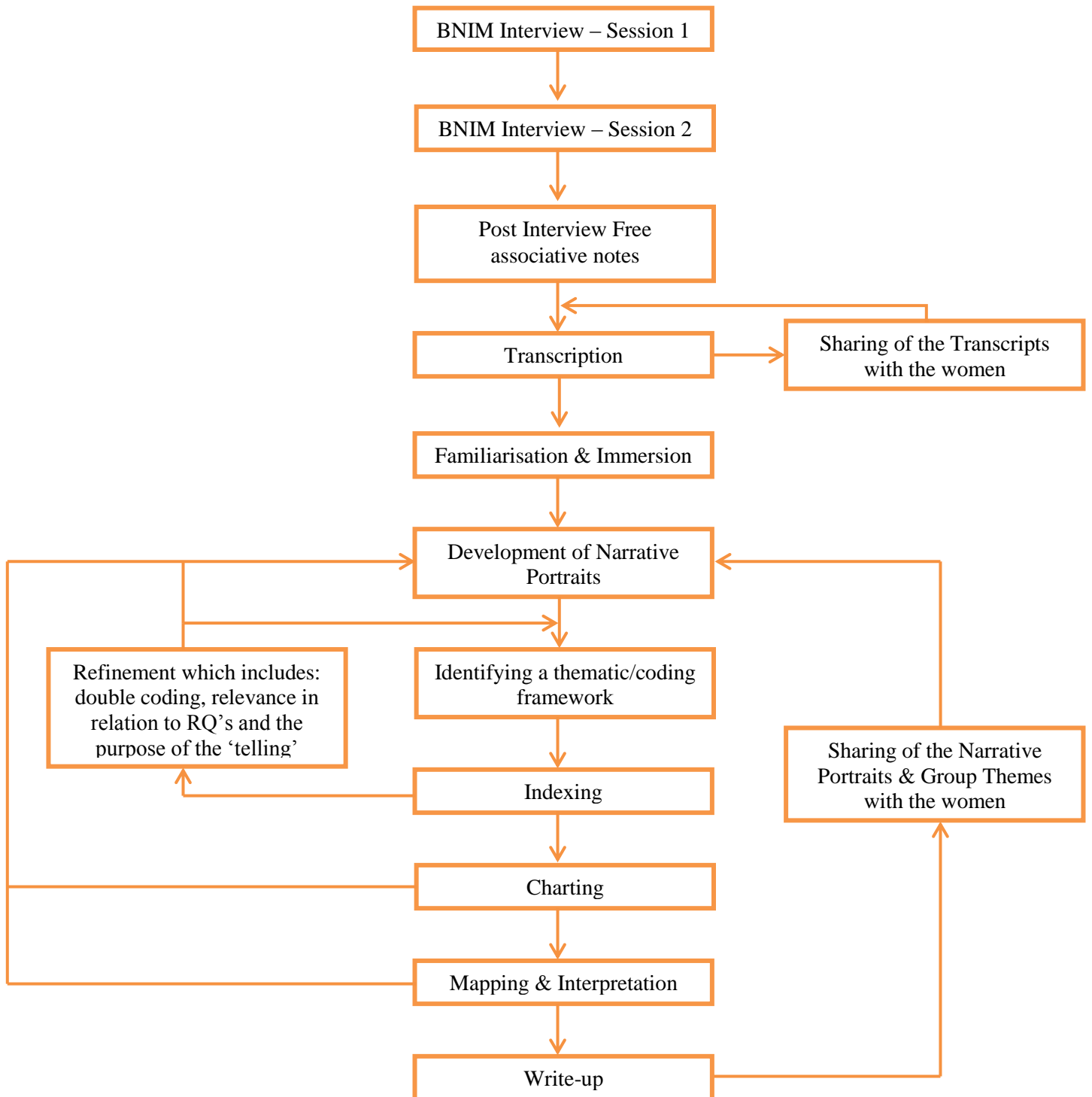
a flow chart illustrating the process of analysis (Figure 2). Each transcript was analysed using steps 1-4 as outlined in Table 2. This process was more cyclical than linear and involved moving between transcripts. The main stages of analysis involved were as below:

- ~ Directly after each interview, I spent some time making notes of the interview experience, any thoughts, memories or ideas it stimulated in me. The function of these free associative notes made instantly after the closure of the interview is to make a record of some of the non-linguistic data that may not be captured by the audio recording (Wengraf, 2001).
- ~ The interviews were all transcribed verbatim and included references to pauses, hesitations, laughter and emotion such as crying. I transcribed three of the seven interviews in order to familiarise myself with the data (Ritchie & Spencer, 2002). The rest of the interviews were transcribed by a bilingual transcriber who had already been involved in the transcriptions for the pre-existing study and therefore was familiar with the process and content. On receipt of the transcripts, I read them all and checked for accuracy, this also served to immerse myself in the data. I read the full interview several times within the space of several weeks to grasp its contents. I also read the full interviews alongside each audio recording.
- ~ During this time the transcriptions were returned to the women, asking them “*does it ring true?*” and “*do you want to delete, change, add, correct or develop anything?*” All the women were happy with their transcripts and did not request any changes.
- ~ At this stage I was familiar with the data and therefore was able to recognise some of the emerging themes or issues from the interviews. It was also important as recommended by Ritchie and Spencer (2002) that I allowed the data to dictate the themes and issues rather than be influenced by any pre-existing ideas, apart from those in the TQUINs. This also allowed me to privilege the key issues from the women’s perspective and experiences (Collins, 1990; Reynolds, 2002). The key issues, concepts or themes that were expressed by the women formed the basis of a thematic framework which could be used to filter and classify the data (Appendix XIII).
- ~ The emerging thematic framework was shared with colleagues and supervisors and refined as appropriate. These discussions also allowed me to revise the themes in the initial thematic framework so that they were relevant to the research question.
- ~ Then began the process of indexing which involved the application of the thematic framework to the interviews (Ritchie & Spencer, 2002). Therefore identifying which portions of sections of the data correspond to a particular theme. This process was

applied to all the data. The thematic framework was further refined during this process. I also engaged in double coding for 5 of the 7 interviews with my supervisors to check interpretations and ensure quality and transparency.

- ~ Once all the data was coded I then developed maps and charts of the entire data set (Ritchie & Spencer, 2002). This involved lifting the data, being mindful of not fragmenting a narrative into a chart with relevant headings and subheadings. This allowed me to see across each interview and between each interview, in relation to what each woman was saying for each code. An example of this is provided in Appendix XIV. The chart also aided in the identification of key issues in each woman's narrative which formed the basis of the Narrative Portraits.
- ~ The final stage was mapping and interpretation, which involved the analysis of the key characteristics as evident in the charts. I met with my supervisors on several occasions to discuss some of the ideas, concepts and interpretations together as were evident from the charts.
- ~ During this time the Narrative Portraits and Group Themes were sent to the women, any changes that they suggested were accommodated.
- ~ The final process of the analysis involved re-presenting the narratives of the women in the final write-up. Some of the dilemmas involved in this process are discussed in the next section.

Figure 2: Process of analysis



Presentation of Analysis

Ensuring anonymity and constructing Narrative Portraits: Throughout the research process a number of mechanisms were employed to maintain the anonymity of the women involved in the study. Therefore names, locations and third party information were changed or omitted. However I recognise that all of these women have been involved in a pre-existing study and that they have presented at local and national conferences, which may mean they are potentially identifiable. More importantly I felt I needed to consider a balance between anonymity and contextualising their experiences. Therefore in order to accurately reflect their experiences of infant loss, I felt it was necessary to include the context within which their experiences occurred. The Narrative Portraits were constructed in order to contextualise each woman's experience.

Narrative Portraits and Group Analysis: There is a dilemma between representing individual and group level analyses. It was felt that in order to privilege individual accounts of bereavement and to make visible the context in which their bereavement occurred that a Narrative Portrait would give justice to each woman. The stories I have told in the Narrative Portraits are not, and could never be the whole story. They are sketches, abbreviated versions of a long and ongoing narrative, that emerged from the Biographic Narrative Interviews. However I have tried to represent what was most important to each woman, based on the key themes that emerged in each narrative and from the Framework Analysis.

Writing the voices of the women: During the final stages of the research project, researchers have a considerable amount of power and control (Ribbens & Edwards, 2000). In particular the language we use and the way we represent women can play a role in sustaining inequality and hierarchies of knowledge (Standing, 2000). One of the dilemmas that I faced as a feminist researcher researching less powerful bereaved Pakistani women was that the ways in which researchers write and represent their words to an academic audience may in fact reinforce and contribute to inequalities in power. Using words such as "*perceived discrimination*" and "*this woman reported that*" inadvertently sustains a power hierarchy and does not privilege the woman's experience. Words also have the potential to obscure or undermine the impact on women of racism, discrimination and disadvantage. However, despite these dilemmas I tried to follow Bhavnani's (1994) definition of a feminist project, that:

"Any study whose main agent is a woman/women and which claims a feminist framework should not reproduce the researched in ways in which they are represented in dominant society – that is, the analysis cannot be complicit with dominant representations which reinscribe inequality" (Bhavnani, 1994, p. 29).

I held Bhavnani's (1994) definition of a feminist project in mind throughout the process of writing the voices of the women, which includes the Narrative Portraits and the group level analysis. Therefore, the use of language and the ways in which I represented bereaved Pakistani mothers through the use of their own words was important in challenging the ways in which Pakistani mothers are sometimes represented.

Quality Checks

Several processes were employed in an attempt to ensure the validity and quality of the research.

Reflexivity

Reflexivity is a core element of narrative and feminist research as well as a means of conducting ethical, rigorous qualitative research (Bishop & Shepherd, 2011; Maynard & Purvis, 1994). The aim of reflexivity is to shift "*the focus from the field of objects known to the activity itself of knowing...To look towards this activity is to look to the self, to take up a reflexive stance*" (Taylor, 1989, p. 130). This Taylor refers to as "*radical reflexivity*" (Taylor, 1989, p. 131). Therefore reflexivity is necessary to tease apart what aspects of observation derive from the researcher, what from the participant and what from the interaction between the researcher and participant (Josselson, 2007). Therefore I utilised a reflective journal throughout the research process to record my thoughts, feelings, experiences, assumptions and biases. The research journal was also used to capture my initial thoughts and free associative notes after each interview in line with the Narrative Inquiry method (Wengraf, 2001).

Multiple Triangulation

Multiple Triangulation involves using multiple methods or perspectives to help produce a more comprehensive set of findings. It can use two or more data sources, investigators, methodological approaches and theoretical perspectives (Thurmond, 2001). I was able to utilise Investigator Triangulation as one of the supervisors in this study was involved in a pre-existing study and had interviewed the same women, this therefore provided another perspective from another investigator. In addition five of the seven transcripts were double coded by one or both of the supervisors. I was also able to utilise Theory Triangulation which involves the use of multiple perspectives to interpret a set of data (Mays & Pope, 2000). This was possible due to the diverse range of skills, theoretical perspectives and experiences that members of the research team brought to the study, for example psychology, social policy research etc.

Peer Debriefers

As well as using research supervision as a way to debrief, other peers were also used as mirrors and sources of alternative perspectives. I drew on a Qualitative Support Group set up at the University which included other Clinical Psychologists in Training who were conducting Qualitative Research. As recommended by Rossman and Rallis (2003) this community of knowledgeable colleagues was utilised to engage in “*critical and sustained discussions*” (2003, p. 69) about the project and emerging data.

Double Coding

Double coding is seen as a valuable process in gaining consensus in coding (Mays & Pope, 1995). Therefore five of the seven transcripts were double coded by either one or both of the supervisors. Supervisors also made comments on all of the Narrative Portraits for each of the women, as well as checking the charts for accuracy.

Respondent Validation

Inviting respondent validation is a key part of feminist research and involves sharing analysis with participants to confirm interpretations and to invite alternative interpretations (Kitzinger & Wilkinson, 1997). Mays and Pope (2000) suggest that this is the strongest available check on the credibility of a research project. Therefore all the women were given an opportunity to comment and make suggestions on their transcript, Narrative Portraits and the group analysis. Feedback was then incorporated in to the report, for example one woman asked for a slight change to the way in which an event was described.

Systematic Approach

The decision to incorporate Ritchie and Spencer’s (1994) Framework Analysis in to the method of analysis was to document the process of analysis in a systematic way. The development of the coding framework and the construction of charts and maps allow me to evidence the development of themes and interpretations. In addition the use of extracts from the transcripts in the final write-up also allows me to evidence the interpretations made and to ensure they are representative of the narratives of the women.

Feminist Objectivity

In line with feminist research the project used Bhavnani’s (1993) three criteria for judging the quality of feminist research throughout. Bhavnani (1993) highlights that within feminist research “*points about racism, exclusion and the invisibility of women of colour*” (1993, p. 96) should not be overlooked or silenced. The criteria that she provides to be used in developing and evaluating methodological and analytic practices are:

- ~ *Reinscription* – This means that feminist research should not be complicit with dominant representations that can reproduce social inequalities. As suggested by Bhavnani throughout the research and particularly the analysis phase the following two questions were constantly revisited; “*Does this work define the researched as either passive victims or as deviant? Does it reinscribe the researched into prevailing representations?*” (Bhavnani, 1993, p. 98)
- ~ *Micro-politics* – This means that the micropolitical processes involved in the research should be made visible. Micropolitics were made visible by discussing them in the research report, but also highlighting the relationships of domination and subordination that the researcher negotiated, in interviews, in supervision and in meetings. These micropolitics were discussed in length in the researcher’s reflexive account.
- ~ *Difference* – Bhavnani suggests that researchers ask “*in what ways are questions of difference dealt with in the research study?*” (Bhavnani, 1993, p. 98). Questions around difference and similarity were addressed at all stages of the research project, from design and development all the way through to dissemination.

Dissemination and being heard

All the women expressed an interest in hearing about the results of the study and therefore the findings will be presented to the women who participated in the study and other bereaved women who were part of the Social Networks and Infant Mortality study. This is because these women appreciate and value being part of the end product and also because it is important that the women validate the findings and feel in control of what is disseminated to others. Initial findings of the study were presented at the Division of Clinical Psychology Annual Conference in Glasgow in December 2014 as an oral presentation. The emerging results were received well and some comments and reflections were provided which helped us to develop the results further. The study was also presented at the Annual European Congress of Psychology Conference in Italy in July 2015, as well as the Society of Reproductive and Infant Psychology Conference in Nottingham in September 2015. In addition there are plans for the findings to be presented at local and regional health professional groups and service meetings such as midwives, nurses, health visitors, paediatric psychology and maternity services. The Maternity Services Liaison Committee (MSLC) in Leeds has expressed an interest in allocating a meeting to discussing the findings of this study. This came about through the efforts of one of the women who is a member of the MSLC. The next step is to publish the findings in a relevant journal highlighting the key issues to policymakers, practitioners and communities.

REFLEXIVITY

Beginning my Reflexive Account

My interest in infant mortality first began from personal experiences of infant mortality amongst family and friends. I witnessed friends and family members struggle to adjust to the loss whilst at the same time feeling that they could not talk about it. When I began working as a Trainee Clinical Psychologist in an Adult Psychological Therapies Service in Yorkshire, I had the opportunity to work with White British women who had lost babies. I was aware that infant mortality was prevalent in Pakistani, African and Caribbean communities, yet they were under-represented in services. When I moved to a Paediatric Psychology Service I had the privilege of speaking to a number of Pakistani women who were on medical wards with a chronically ill child. During my conversations with these women they disclosed that they had previously lost babies. I remember being surprised and upset by this and it prompted me to reflect on my assumptions that “*if BME women don’t talk about it to services then they are doing okay*”. This insight, combined with awareness that Pakistani women who experience infant mortality are not usually able to access bereavement support, prompted my desire to learn and explore what these experiences are like for these women.

My Personal Portrait

One critique of qualitative researchers has been that “*the problem is not that we tailor but that so few qualitative researchers reveal that we do this work, much less how we do this work*” (Fine, 1994, p. 14). The argument being that there is often more focus on how qualitative research is done than on the revealing of the person doing it, an act which Fine (1994) refers to as “*dis-stancing*”. In order to make visible my “*stance*” and experiences of infant mortality, as well as to minimise power relations, I asked myself the same background questions that the women in my study were asked.

I am in my mid-20s, Pakistani, British born and a Muslim. I have both personal and professional experience of infant mortality, particularly in relation to Pakistani women who have lost babies. I grew up with and spent a lot of time with my grandparents. I would join my grandmother when she visited friends, and it was during these visits that I would have the privilege of listening to their poems. There was one that particularly caught my attention and which was exceptionally meaningful as some of the women in my grandmothers circle had experienced infant death, and I shall share the poem here:

Dil mere nu jandara charya	(There is a padlock on my heart)
Kunji re Haath Tere	(The keys remain in your hands)
Na mein Maula Kholni jandara	(I will not attempt to open the lock, my Lord)
Wah lagey mann mere	(In case my mind is touched by air)
Chetey dhaand shanakhah wale	(White teeth of most radiance)
Putar dhaand chambey niya Kaliyan	(My son's teeth are like the fragrance of a blossoming bud)
Koi afsos nahi tusa par Putra	(I have no regrets towards you My son)
Aakhir sarh gayi kismat mere	(Ultimately it was my destiny that died)

The first time I heard this poem, it broke my heart. I remember being extremely touched as well as struck by their ability to articulate their experiences. The poem has remained with me since. Bearing this in mind some of the experiences of the women in the study were not unfamiliar to me and therefore it was important for me to remain reflexively aware of my own understandings, experiences and meanings.

The potential impact of sameness/difference between myself and the women I was interviewing were considered at all stages of the research process. There has been considerable debate in feminist literature in regards to issues around sameness and difference in research, particularly in relation to ethnicity and culture. Bhopal (2001) has argued that “*racial identity can and does effect the research process, whereby women who do have some shared experiences with researchers may be more willing to speak to researchers who reflect this*”. However even with shared ethnicity one cannot assume shared experience, beliefs and values, particularly because there are multiple groups and identities that can make one an ‘*insider*’ or an ‘*outsider*’ (Chaudhry, 1997), for example in relation to degree of religious practice, educational attainment, linguistic ability, occupational status etc. We were bound by the commonality of being Black Pakistani Muslim women from a socially disadvantaged community and yet at times I was different to the women in many ways. Some of these differences included my position as a health professional, the fact that I wasn’t married and had not lost a baby myself. In each encounter with each woman there were commonalities and differences.

Song and Parker (1995) also highlight how participants can make assumptions about the cultural and ethnic identity of the researcher and therefore influence the accounts given for example when withholding or disclosing certain information. Therefore throughout the research process I tried to remain reflexively aware of where I position myself in relation to the women and where I am positioned by the women in relation to themselves.

Reflections on writing 'My Personal Portrait'

It is important to reflect on the use of a Personal Portrait and why it seemed most appropriate for my study, or why it should be appropriate for all forms of qualitative research. When engaging in qualitative research, researchers are often entering their participants' private spaces and lives. Daly (1992, p. 5) writes that as a result qualitative research needs to run on the principles of "*fair exchange*" which is similar to reciprocity. Therefore, in order to ensure that the relationship between the researcher and the participants is non-hierarchical, feminist researchers encourage the sharing and revealing of personal stories (Liamputtong & Ezzy, 2006). Developing my own personal portrait helped me to recognise what I was bringing to the relationship. Feminist researchers argue that reciprocal sharing creates a "*level playing field*" and helps to develop trust and rapport with participants, particularly when researching sensitive topics (Dickson-Swift, James, Kippen, & Liamputtong, 2007, p. 7). In addition researcher self-disclosure is seen as good research practice and as a useful method of assessing rigor and quality (Oakley, 1981; Reinharz et al., 1992). However researcher self-disclosure needs to be carefully balanced as the researcher's position can become unduly privileged, as a result blocking out the participants voice (Finlay, 2002). Ellis, Kiesinger and Tillmann-Healy (1997) suggest one way in which this balance could be maintained by highlighting that researcher self-disclosure should be based within the context of developing a relationship.

When beginning to develop my own Personal Portrait I experienced a number of blocks and barriers during the process. I became aware of the predominantly negative but dominant political and societal narratives that were influencing my writing, identity and disclosures. In particular, I hesitated when identifying myself as a '*Pakistani*' and on reflection I wondered whether this was due to the '*baggage*' that came with being a Pakistani. Some of the dominant discourses and stereotypes around Pakistanis and Muslims revolve around terror, submissiveness, illiteracy and as "*eternal foreigners*" (Rajiva, 2006, p. 169). I wondered whether I should identify myself as a Kashmiri to escape the stereotypes associated with Pakistanis. Ethnic identity descriptions can be viewed as subject positions that are dynamically embraced or rejected for pragmatic purposes (Davis & Harre, 1990). Subject positions in terms of ethnicity are not selected randomly, because they have meaning and implications, for example in terms of societal exclusion (Malhi, Boon, & Rogers, 2009).

Self-disclosure and Personal Portraits can make researchers feel vulnerable (Fontana & Frey, 1994), indeed I too felt I was taking a risk by revealing my personal experiences of infant mortality. However this can provide considerable insight into the experiences our participants may have when sharing their personal stories. Stanley and Wise (2002, p. 177) highlight that if

participants are vulnerable then we too must be prepared to show our vulnerabilities in order to “*even up*” the relationship.

Meeting the women

I first met some of the women in March 2013 when I attended a meeting of the HOPE group. Ghazala Mir had invited me to the group. It was an opportunity for me to introduce myself and ascertain whether the women would be interested in supporting my research. I had arrived slightly late for the meeting because my clinic had over-run. As I frantically made my way to the meeting, I worried about what the women would think of me arriving 20 minutes late and whether I had ruined any chances of making a good impression. On arrival I was met with a room full of Asian women, eating and talking away. I wondered whether I should sneak quietly into a seat and introduce myself when the time felt right, but that didn’t happen. All the women were happy to see me; they already knew who I was and were expecting me. They offered me food and drink and a seat amongst them. They were hospitable and friendly.

I sat and listened to the conversations taking place around me. Who was the Chair? Who was leading this meeting? It was impossible to tell, all the women engaged in free-flowing conversations and felt at ease to speak whenever they liked. It was a very different type of meeting. I noticed an agenda on a flipchart nearby, were they following an agenda? It didn’t seem important to the women as long as they had a chance to say what was on their mind. Then came a time when it felt right to speak about my research and though I was unsure about the response I would receive, the women responded positively. They seemed keen to have an opportunity to speak about their experiences and I was surprised how “*easy-to-reach*” they were. In retrospect I had gone with ideas around Asian women as a “*hard-to-reach*” group, yet when done the right way and with the right gatekeepers it wasn’t as difficult as it first seemed. The term “*hard-to-reach*” also implies ‘*difficult*’, ‘*obstructive*’ and ‘*indifferent*’, yet some research with minority groups has found that it is the systems around them that inhibit accessibility (Crozier & Davies, 2007; Flanagan & Hancock, 2010).

Taking consent

Sometimes I spent time sharing my encounters with and experience of infant mortality through friends and family with the women, establishing a sense of “*connectedness*” and highlighting that the knower is personally attached to the known (Connelly & Clandinin, 1990, p. 4). One of the women said to me “*I’m not telling you anything if it’s for your PhD, tell me...why are you doing this?*” She was very angry at first, but when I narrated my experience she softened and said “*Now I will share with you.*” I learnt that distance or separation does not help establish “*connected knowing*”, sharing of stories does (Connelly & Clandinin, 1990, p. 4).

Reciprocal exposure is a key principle in feminist research, allowing researchers to be questioned gives agency and power to participants (Bolognani, 2007). However it is also possible that researcher self-disclosure may influence how the participant relates to the researcher and what they feel able to share. Nonetheless in general researcher self-disclosure and willingness to be questioned by potential participants has been reported to improve the reliability of research through the personal rapport that is established between the participant and the researcher (Bolognani, 2007).

ANALYSIS

The aim of analysis was to understand the bereavement experiences of Pakistani women following infant mortality. Data collected through the Biographic Narrative Interview Method was analysed using Framework Analysis in order to answer the following research questions:

- ~ What are the bereavement experiences of Pakistani women in relation to infant mortality?
- ~ How do these women make sense of their experience following the loss?
- ~ Do the narratives of these women suggest ways in which services might develop to meet their needs?

This section presents the narrative analysis of the women's accounts, completed using the method outlined in the previous section. Anonymised demographics details of the sample are presented first, followed by Narrative Portraits of each woman and the group level analysis. Reflections on interviewing, analysis and write-up are then provided in the following section.

Table 3: Demographics of women

Pseudonym	Shabana	Fatima	Zaara	Maryum	Alahnah	Sonia	Yasmin
Age	27	31	32	34	43	43	47
Ethnicity	Pakistani	Pakistani	Pakistani	Pakistani	Pakistani	Pakistani	Pakistani
Religion	Muslim	Muslim	Muslim	Muslim	Muslim	Muslim	Muslim
Language	English	English	English	English	English	English	Punjabi
Country of Birth	UK	UK	UK	UK	UK	UK	Pakistan
Education	GCSE	Degree	Postgraduate	Postgraduate	GCSE	Postgraduate	None
Occupation	Housewife	Teacher	Barrister	Trainee Counsellor	Teaching Assistant	Dental Nurse	Care Assistant
Current Family Situation	Husband & 4 children	Husband & 3 children	Husband & child	Husband & child	Husband, 4 children & grandchild	Husband & 2 children	Seperated & 4 children
Baby(ies) name	Hazim & Hazil (Identical Twins)	Hassan & Hussain	Mariam	Eisa & Amina	Munna	Michael	Shamas
Age at death	3 hours	2 months & 6 days/5 months and 9 days	30 minutes	stillborn/40 minutes	6 months	3 months	8 months
Cause of death ¹	Blood Haemorrhage	Unknown/rare life-limiting condition	Weak cervix, premature	Incompetent cervix, premature	Neurimabase Deficiency, pneumonia & chest infection	Congenital Muscle Weakness	Unexplained SIDS
Years since loss	10 years	8/2 years	4 years	7 years	16 years	7 years	18 years

¹ Cause of death is given as described by the women themselves rather than ascertained from professional sources

Narrative Portraits

Shabana

The Interview Context

On the day of the interview I met Shabana surrounded by her 4 children in the main room of her home, holding her youngest 4 month old daughter in her lap. Her 3 children all under the age of 8 sat tightly close to Shabana eagerly watching my every move. Her children sat in silence, they didn't talk neither strive for their mother's attention. I felt there was a sense of detachment, indeed after the interview Shabana did mention her struggle to bond with her children following the loss of her twins. This struggle Shabana described as an ongoing "*fear*" of losing another child. I had asked Shabana whether she wanted her children present or not and she had politely replied "*it's fine*". Shabana asked no questions, even when I asked whether she was worried or unsure about anything, she would politely, albeit briefly say "*no*". When introducing the study I explained that it was about looking at her experience of losing a baby, Shabana immediately corrected me saying "*Babies...I had twins*". Shabana looked aggrieved and I apologised because in a single word I felt I had made her twins and her loss become invisible. I then asked the question about her story to induce narrative and waited, Shabana looked at me blankly and laughed nervously. I rephrased the question and waited again, nothing. The SQUIN is known to induce narrative (Wengraf, 2001), yet for Shabana it didn't help her to begin her story. With reassurance and encouragement Shabana slowly began to tell her story.

My Relationship with Shabana

The interview with Shabana was my first and I was slightly anxious. My anxiety increased when Shabana corrected me at the start of the meeting and then again when she struggled to begin her narrative. Shabana was also quiet and reserved, however despite saying very little at times she offered information. At one point she told me that her husband was her "*first cousin*", I smiled at her curiously and asked what made her tell me that to which she replied "*don't all you professionals ask that question? I thought at some point you might ask me that question, so its best to tell you before you ask it*". This tiny piece of information that Shabana offered provided a glimpse into the types of conversations she had experienced with professionals, it also provided a glimpse into how she positioned me in the interaction, as a "*professional*". I felt she positioned me as all those other "*professionals*" who asked questions but didn't answer her questions.

Summary of Shabana's Narrative

What emerged from the interview was a woman who had experienced the loss of twins in uncertain circumstances and which remained uncertain to this day. Shabana felt that she had been given no answers for the loss of her twins and expressed bitter disappointment at the services and “*professionals*” who were meant to support and care for her.

Shabana described “*bleeding throughout the pregnancy*” as a warning sign which had resulted in an admission and then an emergency C-section. She described feeling confused during this time due to the lack of communication between her and staff. This elevated her feelings of uncertainty. Shabana described not knowing anything about her babies until one of them was brought to her room after he had passed away. Shabana experienced this as devastating and that it affected her relationship with the nurses. It was perhaps the fact that her last memory of her baby would be the image of her holding a cold, dead baby that was the most distressing. Indeed Shabana wondered why she hadn't been taken down to the Neonatal Unit and been involved in the process of turning the machines off, as she did for her other baby. Being able to hold her baby, before the machine was turned off was a moment Shabana preferred to remember. Shabana also spoke very positively about the support she received from her family, for example she described how her family had placed her babies in “*beautiful baskets*” after they passed away and had told her she would meet her babies in heaven.

However once her twins had passed away Shabana said she was moved to the end of a corridor where nurses only came in to do “*routine checks*”. As a result Shabana “*felt as if they avoided me, they didn't really want to come up to me or sit with me or anything*”. Shabana described feeling “*neglected*” and a great deal of “*emptiness*” upon leaving hospital and coming home. Shabana described that despite being ten years since the deaths she was “*still dealing with it*” in her own “*Islamic way*”. She explained that in subsequent pregnancies she has been “*depressed, stressed out*” and struggled to bond with her children. Shabana spoke about the importance of bereavement support for women on maternity wards as well as post discharge. She also spoke about the importance of bereaved Pakistani women being visible in services following infant mortality, including when they leave hospital and in the community.

Fatima

The Interview Context

On the day of the interview I arrived at Fatima's house to be greeted with warmth and happiness. As she gently guided me in to her front room she told me how much she had been waiting to hear from me after our meeting at the Social Networks and Infant Mortality conference. We spent some time talking about life and how Fatima was doing. Then Fatima told

me about the recent death of a Pakistani mother who had stabbed herself in Asda following the loss of her daughter. Fatima spoke about her frustration and upset towards people and services for letting her down, as well as how angry she felt when she saw some very racist comments on Facebook about the Pakistani mother. This brought us onto talking about politics, society and racism. Fatima spoke about the pain racism caused her and her lack of trust in the legal system. I wondered how much this incident resonated for Fatima, and whether aspects of it paralleled with her own experiences of loss. Fatima was in the company of her 2 children, who were busy playing with toys. Fatima was happy to be interviewed in the presence of her children.

My Relationship with Fatima

I had met Fatima and spent time with her at a Conference earlier in the year, so I felt less anxious coming into this interview. In the interview I gradually became aware of Fatima's comfortableness in the relationship too. I also became aware of my feelings about my position in this interaction. I felt like a friend, a confidant, a fellow Pakistani, a woman and a sister. How much of this was due to how Fatima saw me and how much was it due to how I saw Fatima? Or was it due to the trusting and comfortable relationship we had both established? During this meeting Fatima also asked me a lot of questions, where I lived, if I was married, whether I was related to Ghazala, why I was doing this research. I answered all these questions in a real, honest and genuine way, whilst holding a dilemma in my mind about whether this was the right way to begin an interview.

Summary of Fatima's Narrative

What emerged from Fatima's narratives was a woman who had experienced the loss of two babies, which often fused in her mind. She described her frustrations with professionals and her struggle to be heard and acknowledged as a mother. However Fatima spoke at length about the transformative effect of the losses on her identity, her life and her world. For Fatima the ability to survive and transform following the bereavements was only made possible by her religion and the support of her family.

Fatima described her pregnancies as "*normal*" and that the first warning sign for her was when her son Hassan did not cry on the day he was born, She spoke about noticing that "*oxygen*" hadn't been in the room and it had taken staff a while before they were able to resuscitate him. Following this he was taken down to the Neonatal Unit. Fatima described going home "*empty handed*" and that this felt hard for her. Hassan was kept in the Neonatal Unit whilst investigations were conducted. Fatima said that the uncertainty was difficult and that she "*broke down*" several times during this period, however she kept hoping that "*he'll get better*".

Fatima said that even when Hassan was put on life support or when the doctors said to her that “*he hasn’t got worse, but he hasn’t got better and that’s a concern for us*”, she didn’t really hear it, she blocked it out.

Fatima spoke about her husband and family as a source of support during this time, particularly around making decisions in relation to Hassan’s care. Hassan died at 2 months and 6 days old and Fatima went to Pakistan for seven weeks after this. Upon her return Fatima spoke about her disappointment at not being offered any support from the hospital.

Fatima spoke about the number of ways in which she tried to live on and re-start her life after this; she spoke about wanting to get back into education as a way to escape “*the depression*”. With the support of her husband she went back to University to train as a teacher. At this stage Fatima felt she was putting her life back together again.

In 2011 Fatima became pregnant again and this time she elected for a planned caesarean. However she was offered the same date as the date her son Hassan had died 6 years ago. Fatima described not having a say or a choice on the date for her “*planned caesarean*”. Fatima described arguing with the team to move the date but that she was met with an inflexible refusal. She also felt the decision to have it on the day that her son Hassan died was insensitive. However Fatima had her planned caesarean and Hussain was born, she spoke about how Hussein experienced the same difficulties in breathing and was taken down to the Neonatal Unit. Fatima spoke about her growing fear as the events unfolded, such as finding Hussein in the same place in the Neonatal Unit as Hassan.

Fatima described a journey in which she had several “*run-ins with doctors, nurses*” around whether her baby was well enough to be at home. Fatima described a complaint she had made about a senior nurse, who “*had made a comment like, 'you need to get used to it because that’s the way he is now' and that was quite hurtful because it almost made it sound like I didn’t want to take a disabled child home*”. Fatima described several incidences in which her baby was sent home against her wishes only to be readmitted within a couple of hours.

Fatima was allowed to spend her final moments with Hussein with the support of her husband and professionals, which she valued. However again Fatima spoke about her disappointment at the lack of support from professionals following her loss.

Lastly Fatima spoke about some of the ways in which she has been living on following her losses, such as by telling her story and working with charities such as Children of Jannah. Fatima also spoke about the role HOPE-Bradford has made in helping her grieve.

Zaara

The Interview Context

On the day of the interview Zaara was 29 weeks pregnant. I had wondered at our earlier meetings whether this was the right time for her to be talking about her loss, but she had explained that she wanted to “*give something back*” and therefore wanted to be interviewed. She introduced herself as a Barrister and told me a little about her current positions in organisations. She wanted to give me “*an accurate account*” and therefore requested a copy of her transcript from the pre-existing study. She had requested childcare for her toddler, which I had agreed to provide.

My Relationship with Zaara

My first impression of Zaara was that she was a very intelligent and confident woman. Our conversations seemed clinical and professional, therefore I was conscious about being “*professional*” and business-like with her. However as she started to tell her story I saw a very different side to Zaara, she was vulnerable, tearful and emotional. I felt very protective of her at times when she became emotional as she was heavily pregnant. Zaara was also very critical of herself in the interview and at times I wanted to stop the interview to reassure her that she wasn’t to blame.

Summary of Zaara’s Narrative

Zaara’s narrative was about how she had been devalued, deskilled and disempowered as a mother but also as a professional. Zaara spoke about inconsistencies in the information she was given, which affected her ability to trust professionals and increased her feelings of uncertainty. Zaara was also very critical of herself for not knowing what warning signs to look out for and what to do when in labour, she felt that despite being educated she had felt “*stupid*” during the process. As a result Zaara described moving through a personal process of empowerment in which she developed and employed the necessary knowledge, competence and confidence to make sense of her loss. She particularly spoke fondly of the connections she developed with other bereaved women as a way of making sense and living on. The ability to be heard by those in power was the culmination and outcome of her process of becoming empowered.

Zaara had experienced a couple of early miscarriages which she had been worried about but said that she had been told it was “*very common to miscarry very early on*”. At one time when Zaara lost a baby she received contradictory information from professionals such as one said she was miscarrying whilst the other said she was having an ectopic pregnancy. Zaara described how this incident was the beginning of her breakdown in trust; the inconsistent information meant she no longer felt she could rely on professionals.

Following this Zaara requested a referral to the Fertility Clinic for a full investigation, however she felt there was a reluctance to refer her because in terms of their “*policy*” she had not experienced “*three consecutive miscarriages*”. Zaara explained that through her sheer tenacity and diligence she finally got referred, however Zaara explained that in her interactions with the Fertility Specialist she felt dismissed and undermined.

Zaara’s experiences of professionals were that they were not receptive or responsive and that her experiences, views and opinions were less privileged in the professional world of Maternity services than those who were part of that world. Zaara spoke about some of the powerful assumptions that professionals held in relation to her ethnicity which influenced the type of service that was offered to her, despite these assumptions being contradictory. For example she spoke about a time when she was told by a Fertility Specialist that “*you’re Asian...it’s more than likely you’ve got polycystic ovaries and it’s going to be very difficult for you to fall pregnant*”. This was contradictory as Zaara knew she had fallen pregnant, the issue seemed to be not being able to carry though. This assumption about her ethnicity meant that Zaara was offered IVF.

However whilst they were exploring IVF Zaara naturally fell pregnant with Mariam. Zaara said that she didn’t want to take any risks so took complete “*bed rest*” during the time she was pregnant. When Zaara reached 26 weeks she went in to early labour and Mariam was born premature. Zaara described a number of grief reactions such as going into “*Robocop mode*” to detach herself from the intense emotions she was feeling at that time. In addition, feeling and being unprepared for the birth of Mariam left Zaara feeling like a bad mother. Zaara was also troubled and upset when she was not able to engage in some of the religious practices that she had planned for the birth of Mariam.

Zaara wasn’t able to attend Mariam’s funeral, but remembers being left for an hour or so alone in her room. Furthermore Zaara said that she wasn’t offered any counselling or chaplaincy support from the hospital. However Zaara did feel supported by her husband and family, particularly around practical help at home which reduced her stress.

Zaara remembers not being given answers and left the hospital feeling very “*empty*”. As a result she said she made contact with another bereaved woman through a friend. These conversations allowed her to access support organisations such as Children of Jannah. Zaara said she found this very useful and that she found a great deal of “*solace*” in her religion. Through these conversations she was also able to establish that maybe she has a “*weak cervix*”. The process of talking and sharing with another bereaved woman allowed Zaara to process and make sense of her loss.

With this knowledge Zaara requested a referral to a specialist consultant who supported her to naturally give birth to a baby boy. Zaara went through a process of empowering herself following the loss of Mariam. Finding knowledge and information and being heard by those in power allowed Zaara to feel empowered.

Maryum

The Interview Context

On the day of the interview I met Maryum in her driveway as she returned from the child minder. Maryum had requested child care for her little boy and this had been agreed. It had taken a while to organise this interview, in our initial meeting Maryum had been ambivalent about the “*research*” and then had text me late one evening to say she wanted to be interviewed. Maryum spent time talking about her family, the “*rocky*” relationship with her husband and her anger towards services and professionals. She also told me that she had set up and facilitated a bereavement support group in the community for parents who had recently lost an infant. She was also training to be a Counsellor. Maryum’s interview was the longest, it lasted approximately 2 hours.

My Relationship with Maryum

Before the interview Maryum asked me why I was doing this research and then immediately said “*I’m not talking to you if it’s just for your PhD!*” Maryum proceeded without waiting for a response; she wanted to know if her experience meant anything to me and what I was going to do with it. Maryum said at times she felt very resentful of other people and that she was contemplating some very big decisions right now and was awfully busy. I felt Maryum was very angry and aggrieved, so I spoke to her about my own personal journey in deciding to research this area. Maryum then relaxed and said “*now I will share with you*”. I wondered whether this had been a test of my dedication and my patience. I regarded Maryum with a mixture of awe and trepidation. She was remarkably resilient and intelligent, as well as bluntly honest. Perhaps my unease was partly due to her fearless attitude to speak her truth, even if it made others uncomfortable.

Maryum’s experiences were both upsetting and unsettling. Maryum was many different women in the interview, at times she was a helpless, powerless woman and at others an angry, fiery woman. When she was angry her speech became loud and fast and when she felt helpless everything slowed down. Maryum also described her pregnancies and losses in graphic detail, and therefore I not only felt her emotional pain, but also gained a sense of her physical pain.

Summary of Maryum's Narrative

What emerged in the interview was a narrative that was replete with examples of strained, problematic and abusive relationships, with her husband and with professionals. Maryum explained that she did not find comfort at home and neither from professionals, which intensified her feelings of angst, loneliness and desperation. Experiences of “domestics”² at home were juxtaposed with professional mistreatment in hospitals, which left Maryum feeling “unsafe”. In such an unpredictable world in which Maryum suffered multiple losses, the only comfort she found was in her religion. Her religion provided her with meaning to her experiences as well as the encouragement that things would get better for her. Maryum was also very self-reflexive and motivated, despite all her experiences she had set up and facilitated a support group for parents who had recently lost a baby. As a result Maryum represented a woman who felt she could no longer depend on systems (family and professional) to meet her needs and neither of bereaved families. Therefore the motif of resistance is particularly important in Maryum's narrative.

Maryum began her narrative by setting the scene in relation to some of the difficulties she experienced in her marital relationship, the onset of her “agoraphobic stage” which was linked to the realisation that she wouldn't be able to conceive naturally and her own attempts to “come out” of this stage in her life. To Maryum's surprise she did conceive naturally exactly 12 months later, however she felt no monitoring was done during this period. Maryum described experiencing “pulling pain” throughout this pregnancy, however she felt that despite her numerous attempts at telling the professionals involved in her care about this, nothing was done. It came to a point that Maryum had to be taken into hospital following the loss of significant amount of blood at home, At the hospital when she received the news that her baby would not survive, Maryum became distraught. Being able to conceive naturally despite being told by medical professionals that it wasn't possible was a “miracle” for Maryum. She also felt that despite all the hardships she had endured in her marital relationship, that Allah had rewarded her with a baby. Therefore the survival of her baby represented a lot more for Maryum, it represented a fresh start in her relationship with her husband and it represented an end to her “agoraphobic stage”. Maryum was in labour for four days and she felt her husband redeemed himself during this time, they finally had a conversation about letting go of the baby and Maryum was induced. Maryum said she did not get a chance to do all the things she would have liked with Eisa, like bathe him, clothe him and do hand and foot prints. However, she valued a conversation with a nurse who spoke from a religious and spiritual perspective.

² This was a word used by Maryum which described verbal arguments that she had with her husband in the past.

Maryum found the process of leaving hospital amid parents holding new born babies traumatising, she spoke about how she knows now that there was a separate alley to walk out of, but she had to take the same route as parents with new born babies. Losing Eisa threw Maryum into “*zombie mode*” in which she spoke about feeling agoraphobic, depressed and neglectful towards herself. Maryum said she received no support from anyone during this time, in fact she described how two community midwives turned up at her door asking to weigh Eisa. Maryum remembers going hysterical, laughing and crying. However Maryum saw this as a sign from Allah that one day two community midwives would come to weigh her baby, holding onto this hope allowed Maryum to once again “*come out*”.

Maryum became pregnant again and this time she said she started “*pushing*” for extra scans, swabs and investigations herself because she felt that these were not “*willingly*” offered. During this time her mother-in-law came from Pakistan and Maryum spoke about arguments “*flaring up*” between her and her husband. At 21 weeks Maryum said she started to feel unwell, but didn’t go to the hospital immediately because she was worried about hassling her husband. Maryum also said that in the early stages of this pregnancy she had visited hospital a few times with worries that something wasn’t right and therefore thought maybe it was just one of those days. However her bleeding intensified and she was rushed to hospital where Amina was born prematurely. This time Maryum spoke in detail about her final moments with her daughter and how she experienced the chance to hold her and kiss her goodbye as a “*blessing*” from Allah.

Despite experiencing her final moments with Amina positively, Maryum set this alongside her troubling experiences of the system and professionals. She described a multitude of comments that she experienced as “*insensitive, derogatory*” and racist.

Maryum also described one midwife as “*Misery*”³, which is the ultimate metaphor of a powerful, frightening woman who one is dependent on. Maryum described several worrying incidents that other professionals witnessed, but that they all remained silent due to the power that “*Misery*” had in that system. As a result Maryum felt she wasn’t protected.

Following this Maryum met with a Consultant Dr NS, who other women have also spoken positively about in this study. He helped her establish that she may have a “*weak cervix*”. During this time Maryum miscarried a few times early on, however she eventually fell pregnant in 2012. Maryum said she was supported by Dr NS throughout her pregnancy and she gave birth to a baby boy. However Maryum said she wasn’t given any post-natal support, which was particularly worrying as she felt she may have suffered from postnatal depression.

³ A character from the Stephen King novel called *Misery* (King, 1987)

Maryum felt that she experienced injustice and maltreatment at the hands of some professionals and that she received limited support from her family; as a result this fuelled her resistance against the system. Maryum said she went out of her way to find the knowledge of how systems and services should work in order to empower herself. Maryum also independently set up a support group for bereaved parents. Indeed for Maryum in order to survive and live on she had to acquire the knowledge in order to navigate the system.

Alahnah

The Interview Context

On the day of the interview I was relieved to be finally meeting Alahnah as she had cancelled a number of times. Alahnah apologised for the cancellations and explained that it was close to her daughter's death anniversary and at these times she felt particularly vulnerable and fragile. However despite that Alahnah said that she did want to help and wanted an opportunity to share her story. Alahnah offered me a cup of coffee before the interview started and then went off into the kitchen, she was moving dishes, cleaning up and sorting things out. I looked at my watch, was she anxious? Was she stalling? When we finally started the interview, Alahnah laughed nervously and told me she didn't like the sound of her voice. I smiled and encouraged her to start her story. Despite initially hesitating, Alahnah quickly overcame her anxiety and began to tell her narrative.

My Relationship with Alahnah

When Alahnah had cancelled a number of times I had wondered whether she didn't want to meet me. However in the interview she had explained that close to the anniversary of her daughter's death she felt very angry towards professionals, she said "*I think why should I help others, when no one helped me?*" Alahnah had been very emotional and tearful in her interview and as a result at times I too had to fight back my own tears.

Summary of Alahnah's Narrative

Alahnah's story was raw and emotional; she represented a woman who had not been supported to grieve for 16 years. Alahnah recognised this and explained that she had only recently been referred for counselling despite the fact that she needed it a long time ago. Alahnah spoke about the importance of normality and how she strived to have a "*normal*" baby. Alahnah at times described experiences that indicated that she may have suffered from mental health difficulties, yet despite these experiences her entire narrative was void of any

professional involvement. Alannah's relationship with her husband and her husband's reaction to the loss were a key part of her narrative.

Alannah started her narrative by describing her pregnancy as "*normal*" despite not feeling her daughter kicking. As the due date came close Alannah was told by her midwife that her baby was breach and that they may need to do a caesarean section. Alannah explained that this "*scared*" her and as a result she ended up going into labour that day. Alannah noticed that as she was having contractions her daughter's heartbeat was decreasing. She was therefore told that she needed to have a c-section, however Alannah was determined to have her daughter "*normally*".

For Alannah there was something very important about having her baby "*normally*", therefore she was particularly influenced by dominant discourses around normality and normal birth. When her daughter was born Alannah described feeling relief and then immediately asking "*Why isn't she crying?*" Alannah eventually met with a Genetics Specialist who explained to her what had happened with her daughter and that they thought she had "*Fuhrman's Syndrome*". Alannah said she recognised this condition because someone from her husband's side of the family had been diagnosed with it too. Alannah was told that they would need to do several tests to confirm whether her daughter did have Fuhrman's Syndrome but that the next "*36 hours are crucial*". Alannah had already started grieving for the impending loss and in order to protect herself from the pain she chose not to see her daughter. However it was through discussions with her husband that made her change her mind. The conversation with her husband allowed Alannah to overcome her fear and go to see her daughter. Alannah documents the importance of maintaining ongoing communication in alleviating some of the emotional impact on mothers. Alannah also discussed how important it was for her that other people saw her Munna as "*normal*". Alannah was particularly anxious about how children with disabilities are treated in society and as a mother she attempted to protect her baby from societal stigma. Alannah also spoke in detail about the impact of Munna's condition on her husband, she felt he was "*more attached*" to Munna than she was. Therefore she made sure he had someone to talk to in their family. Following several investigations Alannah was told that Munna had Neuraminidase Deficiency, a rare life-limiting condition. The news of Munna's impending death meant that Alannah tried to spend every minute with Munna. She described the time when they were allowed to bring Munna home and how happy she and her husband were. Alannah said that her husband did everything for Munna and that they never missed an appointment. At this point Alannah became very tearful in the interview as the realisation of the loss and her grief came to the fore. For Alannah her grief was as raw today as it had been 16 years ago. Alannah explained that when Munna came home they became "*a normal family*" with their

daily routines. Alannah valued being a mother to Munna and explained that even when the hospital offered her a night feeding machine, Alannah didn't use it as she wanted to get up and feed Munna herself. However Munna was readmitted and passed away a couple of days later. Alannah described that she went into shock at the news of her daughter's death and that she "*blocked it out*". Alannah described experiencing mental health difficulties following the loss, yet during this time in her life she did not mention any professional support. Alannah described experiencing Munna's funeral as very difficult, she couldn't understand why people were visiting her and she felt very vulnerable and exposed. She also described feeling very angry towards women who had babies. But Alannah explained "*that wasn't me that was the grief*". Alannah described an incident where she ended up at her daughter's grave with a spade, hoping to dig her up. This incident represented the culmination of her grief.

Alannah also spoke about her religion and that it gave her a lot of strength to deal with her loss. Alannah said that the only contact they had with professionals following Munna's death was with a genetics specialist. Alannah spoke about her attempts to live on by finding a replacement for Munna.

Sonia

The Interview Context

On the day of the interview we spent the first 40 minutes talking about Sonia's current stresses, responsibilities, pressures and relationships with her in-laws. Sonia was an avid baker and as she showed me photos of her cakes; I realised she was pretty good at it too. Sonia also mentioned not feeling appreciated by staff at her local hospital, "*I feel that every time I walk on to the ward they roll eyes 'oh her again' ...but I'm doing them a favour*". Sonia said she valued raising money for the hospital and befriending parents via the organisation Bliss, for "*babies born too soon, too small, too sick*", but she wondered how much of her work was appreciated. Sonia spoke about feeling that she would "*burn-out*" and speculated why she takes care of others, but not herself. Before the interview she gave her teenage daughter permission to leave the room if she didn't want to listen, but her daughter chose to stay. I wondered how much having her daughter in the room influenced the telling of her story.

My Relationship with Sonia

I was amazed by Sonia; this was a woman who held a job, ran a family, volunteered as a Bliss Befriender, did TV interviews, baked cakes and raised funds for her local hospital. Sonia was proud of her achievements since her bereavement and I felt that sharing these with me allowed the memory of her baby to remain alive.

Summary of Sonia's Narrative

What emerged from Sonia's narrative was a mother who fought for a long time to keep her baby alive and following his death spent time searching for her purpose in life. Sonia had an overwhelmingly positive experience of the professional world, and it was with this support that she was able to process her grief, speak out and support other families. Sonia's narrative represented that things could go well and when supported mothers could live on.

Sonia started her narrative by explaining that Michael was her third child. Throughout her pregnancy she had been worried about him as she hadn't felt any movement; however she had been told by her Midwife that "*sometimes babies are like that, they can be lazy*". Six weeks before Michael was due Sonia woke with pain that didn't feel right. Sonia said she rang the hospital and was told to "*take some painkillers*". At this stage she wondered whether she should have gone into hospital, but felt that she listened to "*professionals*". By the afternoon her pain had worsened and she was rushed to hospital by her husband.

At the hospital Sonia gave birth to Michael, Sonia remembers asking the nurses "*why is my baby not crying?*" and that no one responded. Michael was eventually brought round and Sonia was allowed to hold him before he was taken to the Special Care Unit. Sonia said her family came to the hospital to support her and then the nurses took her to see Michael in the Special Care Unit.

Sonia described both the positive and negative consequences of being moved to a side room in the hospital. She valued being away from mothers who had babies, but struggled with the "*empty cot*" in her room. In her grief Sonia described not being able to voice the impact of "*the empty cot*" to the professionals around her. The next day Sonia said they were called into a meeting with their consultant to explain that Michael had a "*muscle condition*" and that he would not have long to live, Sonia said that she felt that there was "*no hope for us*".

After that Sonia spoke about how Michael was always "*under investigation*" as doctors tried to find "*a name for it*". Unfortunately despite all the "*biopsies, tests, everything*" they didn't find a name. Michael had "*good days and bad days*", regardless of that Sonia tried to do things with Michael, Sonia spoke about how she spent time collecting memories of Michael. Sonia said that she is grateful that she collected these memories as a way to remember him. Sonia spoke about the time that she spent with Michael as her "*duty*" as a mother. Being a mother to her baby was very important for Sonia. However Sonia recognised that during that time her 2 elder children "*missed out*".

Sonia said she would get emotional seeing other babies get better and go home. As a result she would often try to hold on to hope and at these times she said her religion was a useful source of support.

Sonia also spoke about the positive impact some professionals had on her, particularly those who were genuine and caring. Sonia found a lot of comfort in nurses who went out of their way to do something for them, such as buying Michael a small clothes cupboard.

During this time Michael “*collapsed*” a number of times and had to be resuscitated, and it came to a point when Sonia felt Michael had “*had enough*”. Sonia was called back into hospital to spend her final moments with Michael. Sonia spoke about losing her purpose in life following the death of Michael, she said “*I just didn’t know what to do with myself*”. But Michael’s death “*opened so many doors*” for Sonia. Sonia said she was involved in research and also was part of a group for bereaved mothers. Sonia said she has been invited to speak at conferences and that speaking has allowed Michael to live on in her life. Sonia was supported by professionals to tell her story through various means, such as research, TV, books and conferences. This helped Sonia to process the grief and to emotionally recover.

Yasmin

The Interview Context

On the day of the interview Yasmin was very hospitable, she fed me pakoras, chutney, biscuits and tea during the interview, at times she would stop the interview to encourage me to eat. She made it a point to not let anyone leave her home on an “*empty stomach*”. We chatted in Punjabi for a while before the interview, about our community, about Pakistan, about the perils of raising children and about life. The entire interview was conducted in Punjabi.

My Relationship with Yasmin

Yasmin was curious about me, what I was studying, whether I was married and what my family were like. I answered all these with honesty and genuineness. Yasmin spoke about trust a lot, about the need to be “*believed*”, she came from a position of not trusting professionals or sitting with the feeling that she wouldn’t be believed, indeed at times she would illustrate this in our interaction by saying “*if you don’t believe me then...*”.

Yasmin tried to prepare me several times about what I was about to hear, stating “*mine is a terrible tale*”, she set the scene for me to witness an important narration. As a result Yasmin’s account of her experience of loss was produced as a “*testimony*” that challenged the very silencing mechanisms that shaped it. Yasmin’s attempts to be heard and give her side of the story was therefore much more than a response to the threat of being labelled as an “*un-*

caring mother”, but more importantly it implicated and located the interview interaction and the entire research within the wider social context. By producing me as a witness to a testimony, allowed the interview interaction to become politicised and push it towards activism i.e. challenging the research to do something about this context. Indeed, she asked me several times “*why Romana, why?*” I had no answers but every time she asked “*why?*” I felt compelled to find them for her.

Summary of Yasmin’s Narrative

Yasmin’s account of bereavement was short and unexpected; however it was her subsequent experiences that kept the loss, the grief and the pain alive. Yasmin’s bereavement represented the ultimate loss of control over her destiny, her life and her choices. In addition repeated negative experiences with social workers, lawyers and medical professionals meant her grief was left unresolved. She talked about the power the professional world had over her, her life and her relationships. She spoke about how professionals dictated whether she was good enough to be a mother, to be married and to have a voice. Unfortunately, Yasmin wasn’t automatically eligible for sympathy; she felt no matter what she did, she just didn’t meet the professional standards of a good mother.

Yasmin was born in Pakistan and came to the UK following her marriage. At that time she was pregnant with Shamas who was born in 1996. Yasmin explained that she was very poorly during that pregnancy with abdominal pain. Three months into the pregnancy Yasmin had a lot of bleeding and was rushed to hospital with worries that she may have miscarried. She reported staying in hospital for a week and being discharged without any explanation for the bleeding. Shamas was then born normal at full term, despite the fact that she had been “*coming and going*” to hospital with pain throughout the pregnancy.

Yasmin reported that her son was a “*healthy baby*” apart from having eczema. When Shamas was 8 months old he had a bout of diarrhoea for which she took him to her local GP one evening, however Yasmin reported that her GP prescribed medication for diarrhoea without checking Shamas. Yasmin emphasised the importance of this encounter with her GP for a number of reasons, but mainly because it was her attempt as a mother to seek help for her baby. Yasmin explained that the following morning whilst playing, Shamas fell to the floor and stopped breathing. This was an unexpected and sudden bereavement; Shamas went from playing to giving his final breath. In the shock Yasmin described her mind going “*crazy*” and not understanding what was going on. Yasmin explained that they rang for an ambulance and her baby was checked by the paramedics for 20 minutes. However she did not know what happened in the ambulance as she wasn’t allowed in. The uncertainty of not knowing what

happened to Shamas in the ambulance was coupled with her guilt as a mother for not finding out what was happening. Yasmin also spoke about her final moments with Shamas on arriving at the hospital, she said she tried to embrace her baby but was told by a nurse “*you can’t touch it*”. Yasmin was not able to embrace her baby for the final time, leaving everything unfinished and unresolved. Yasmin described how she willingly went to the police station and was questioned for several hours, before being released without charge. There were several investigations and a “*court*” case after this, however Yasmin described not having access to all the information and being confused about what was happening. Indeed she wasn’t even able to describe what type of “*court*” case she had been involved in.

Yasmin tried to come to terms with her loss by working and trying to put her life back together again. However in 2007 she fell pregnant again and a month before the birth of her baby, social services became involved. She was told that she couldn’t keep her baby and upon birth the child was removed without allowing Yasmin to meet her baby.

For Yasmin this was the beginning of a number of encounters with social services that led to the removal of a number of babies and Yasmin’s desperate attempts to “*save*” her babies. Indeed Yasmin spoke about her experience of being constructed by social workers as an “*uncaring mother*” and how this was a violent attack on her sense of self as a person, as a woman and as a mother.

Yasmin illustrated the desperation of a mother who is unsure how to “*prove*” her love for her baby to professionals who constructed her as an “*uncaring mother*”. For Yasmin professional attitudes towards her exacerbated the grief and did not allow her to live on. In addition Yasmin felt she was compelled by professionals to remain a grieving mother, despite experiencing it as paralysing and painful.

Yasmin ended her testimony by requesting that we “*do justice*” and support her in having her voice heard. Yasmin spoke about the importance of mothers standing together and speaking together in order to bring about change. Yasmin’s only hope was her voice and the chance to have her “*testimony*” heard by others, the experience of talking and sharing with others allowed her to further process her bereavement experience as well as challenge the context in which it occurred.

Group Analysis

Overall, the group analysis yielded two types of themes: master narratives and subthemes within these. Six master narratives were identified which were: uncertain narratives, powerless narratives, grief narratives, transformative narratives, sense-making and meeting our needs. Shabana, Zaara, Fatima, Sonia, Alahnah, Maryum and Yasmin had both similarities and differences in their experiences. This section elucidates some of these connections at a group level as well as instances in which their experiences may have diverged. The master narratives and subthemes are depicted in the thematic map (Figure 3) and Table 4 illustrates the frequency of the master narratives and subthemes across all 7 women. The quotes for subthemes were selected to best represent common experiences across the group.

Figure 3: Thematic Map of Group Themes

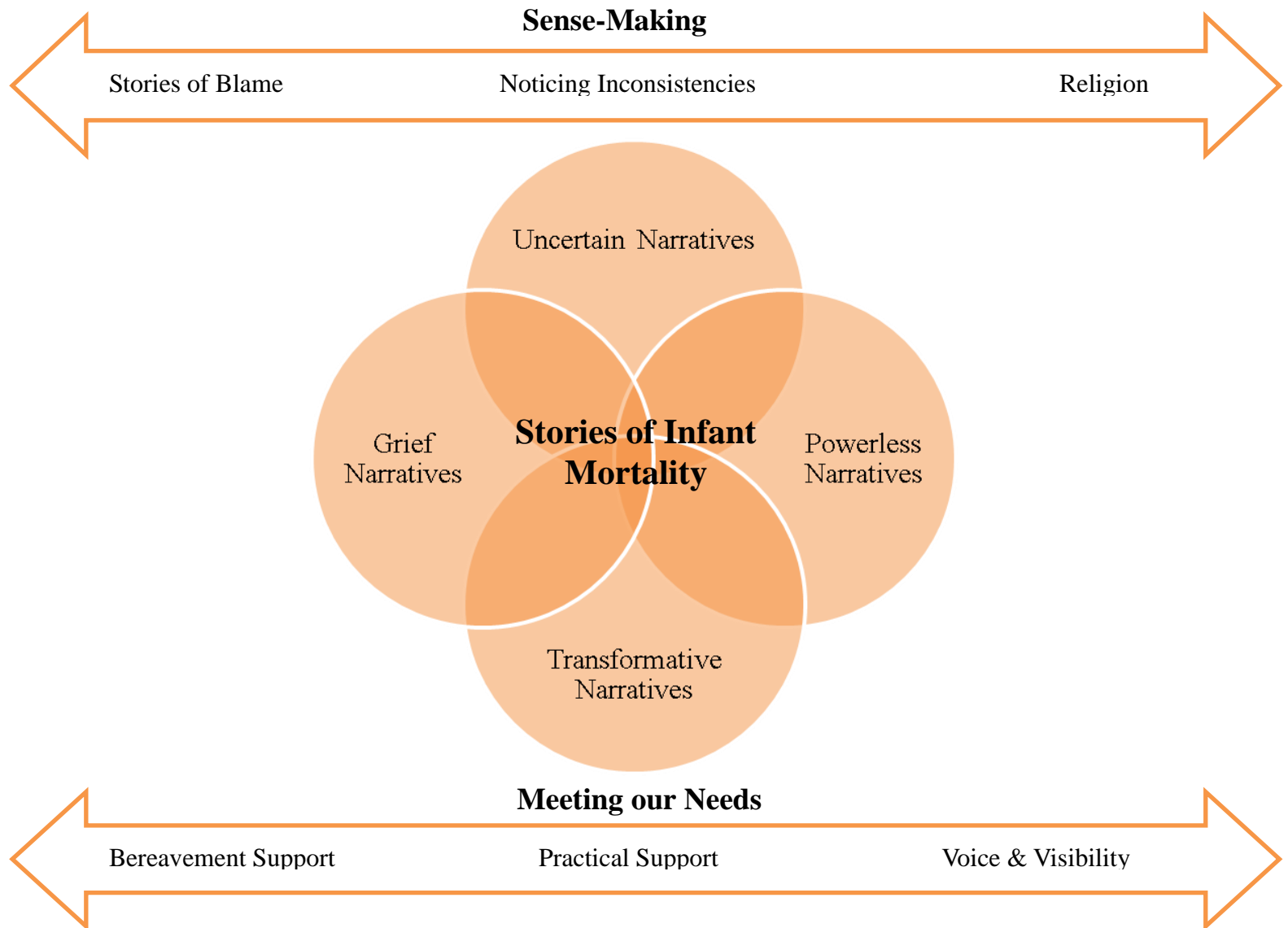


Table 4: Frequency of Master Narratives & Subthemes

Master Narrative	Subtheme	Sh	Z	F	So	A	M	Y
Uncertain Narrative	“This is not right, this is not normal”		✓	✓		✓	✓	
	“I was scared”							
	“I wasn’t given the answers”	✓	✓	✓	✓	✓	✓	
Powerless Narrative	“You would think a Mum’s opinion matters”		✓	✓	✓		✓	✓
	“She knew best and you had to listen to her”		✓	✓	✓		✓	✓
	“I couldn’t have any control over what was going on around me”	✓	✓	✓	✓	✓	✓	✓
Grief Narrative	“The Last Moments”	✓	✓	✓	✓	✓	✓	✓
	“It was just like echoing voices in the background”	✓	✓	✓	✓	✓	✓	✓
	“They say time heals it...it doesn’t”	✓	✓	✓	✓	✓	✓	✓
Transformative Narrative	“I was Alhamdulillah very fortunate that I had my family around me”	✓	✓	✓	✓	✓	✓	✓
	“I’m not who I was eight, nine years ago”		✓	✓	✓	✓	✓	
	“We were all bereaved mums”		✓	✓	✓	✓	✓	✓
Sense-Making	Stories of Blame		✓	✓	✓	✓	✓	✓
	Noticing Inconsistencies	✓	✓	✓	✓		✓	✓
	Religion	✓	✓	✓	✓	✓	✓	✓
Meeting our needs	Bereavement Support	✓	✓	✓	✓	✓	✓	✓
	Practical Support	✓	✓	✓	✓	✓	✓	✓
	Voice & Visibility	✓	✓	✓	✓	✓	✓	✓

Uncertain Narratives

Within this master narrative, three subthemes were identified, expressed by participants as: *“this is not right, this is not normal”*, *“I was scared”* and *“I wasn’t given the answers”*. What connected all three subthemes was the feeling of uncertainty, not knowing, unpredictability and irresoluteness. All three are discussed below.

“This is not right, this is not normal”

Bereaved Pakistani women spoke in detail about the importance of normality in pregnancy, during labour and afterwards, as well as the impact of experiences that deviated from the *“norm”*:

“they were monitoring me and each time I was getting a contraction her heart beat was going down and they said to me that ‘oh, we need to do a c-section’. I was quite upset because...I really didn’t want a c-section. After three, having normal three deliveries I said ‘you know I don’t want it. Could you please just try to deliver it normally’”
(Alahnah, p. 3)

Alahnah speaks very eloquently about the importance of delivering her baby *“normally”*, she wanted to avoid any interventions that would jeopardise her chances of a normal pregnancy. Even when her daughter was diagnosed with a life-limiting condition, Alahnah persisted:

“I wanted her to have a normal life, like my other 3 boys. And that’s what I tried to give her, a normal life.” (p. 24)

Comparing their experience with what *“normal pregnancy”* should be like was one way in which Pakistani women navigated the ambiguities around atypical and different pregnancies. Maryum spoke about this from her experience:

“I’m finding it hard to walk at this stage and I’m 19 weeks’ pregnant and I really panicked, thinking ‘oh, God. This is not right. This is not normal...’ because I thought I would be okay when I hit 14 weeks. Because in your first pregnancy, all you know is that people tell you ‘you’ve got to get to 14 weeks, you’re all right then.’ I don’t think that anymore.” (p. 3)

When Zaara miscarried a number of times she spoke about how “normal” pregnancy discourses influenced how she made sense of her loss and whether to take the miscarriages seriously:

“It didn’t worry me too much because when I went to the doctors, they said it was ‘...very common to miscarry very early on. Some people don’t realise it. Sometimes it’s just seen as period. Some people miss it.’ So, that gave me some reassurance to say ‘okay, well, I’m normal. It’s just a miscarriage.’” (p. 2)

Experiences that seemed counter to the “normal” pregnancy discourses in society brought about a sense of uncertainty for the women. Zaara described the process women go through when faced with an experience that isn’t “normal”:

“When you don’t know.....and experience things which you think aren’t normal, I think that panics you...I felt panicked when...when my waters went. I thought ‘this is not right.’ It was panic that kicked in first. Then it was fear...‘how could this be happening to me. This is not a miscarriage because I’ve had my miscarriages. They said it’s normal before 12 weeks. This is not normal. Nobody’s warned me about this...” (p. 23)

Maryum also spoke about how her ideas around pregnancy and birth had been influenced by dominant “normal” pregnancy discourses. She described her upset when her experience was contrary to that which she had been indoctrinated into:

“You imagine giving birth to be a very happy moment in your life; a moment that you’re going to cherish and remember for the rest of your life...I used to watch that ‘One Born Every Minute’ religiously, and there were women on there that used to talk about how....you get this rush of hormones and you feel absolutely amazing when the baby comes out, and I was so eager to feel that and I was just crying because I couldn’t feel it. All I felt was pain. Lots and lots of pain” (p. 6)

Normality provides women with comfort during pregnancy; bereaved Pakistani women described how their experiences were different from “normal” pregnancy discourses and therefore brought feelings of uncertainty and difference.

“I was scared”

All the women spoke about feeling “*scared*” and “*frightened*” during different stages in their bereavement experience. Women described feeling scared when they first experienced something that was different, unusual or unexpected; Maryum described her feelings when she went into early labour:

“I was in absolute agony. I couldn’t move and I just...you know when you just know something is not right, I just felt really scared and...I felt very vulnerable and I found it very hard.” (p. 3)

Leaving hospital “*empty-handed*” was another big fear for all the women, it represented an atypical pregnancy:

“Just coming home alone was my second biggest fear. One, taken down to Neonatal Unit and then...my biggest fear was coming home alone and that happened as well, so that was like a second knock back and confirmed my fears that, you know, this isn’t going to go happily ever after, kind of thing.” (Fatima, p. 25)

Maryum also spoke about how she felt when she came home:

“I remember coming home and I had a panic attack. I felt like I wanted to run out of the house...I was scared to go out, but I was scared to be inside and I just...it was horrendous. Absolutely horrendous. I can’t even tell you how I felt.” (p. 37)

The experience of infant mortality became a part of the woman’s life and as a result overshadowed her subsequent pregnancies:

“I think throughout all my pregnancies I’ve been really scared... I think when you fall pregnant again you are, you’ve got the last experience shadowing...the current experience and you’re always scared. I’m still scared and I’ve had a successful, Alhamdulillah [pregnancy]” (Zaara, p. 21)

“I wasn’t given the answers”

Women also spoke about the impact the lack of explanation or reason had on their sense of uncertainty. Zaara spoke about lack of continuation of care and the subsequent impact on not getting a proper answer:

“The consultant.....that...delivered Mariam...I never saw her again, which I thought was strange...because I had so many questions I wanted to ask her and she was there, she had been through that experience with me, she would have understood and perhaps been able to answer my questions. But, then they sent in another consultant and he said 'by the looks of it, we can't really tell what's happened but, we are going to have to do...would you consent to a post mortem?' and I said 'no. I don't want a post mortem. You can do what you want with the placenta. You can take as many bloods as you want from me, but....' I know it was...her lungs hadn't developed....she wasn't able to breathe by herself and, again, there was a contradiction because how was she then born alive if she wasn't then able to breathe? How come her heart was beating then? How does your heart beat if you can't breathe? Maybe there is a way but...at the time I wasn't given the answer and I think that's what you seek comfort in because you want to know what happened.” (p. 10)

Fatima also spoke about how there was no explanation for her loss as the “research” was still ongoing, leaving her bereavement unanswered, unresolved:

“It was quite obvious it's a genetic disorder, but what kind, the geneticist were still doing their research.” (p. 8)

Yasmin also spoke about how she had experienced heavy bleeding during her pregnancy; however she was given no answer to why that may have happened:

“I stayed there for one full week, they must have thought that maybe 'the baby's miscarried'. But when they did the x-ray they found out that the baby is safe, the baby is okay. But they couldn't understand or they couldn't explain why there had been so much bleeding.” (p. 2)

Maryum spoke about how her loss was left unresolved:

“I remember going in thinking I’m going to get a date from NS telling me when he is going to put a stitch in. I was about 11 weeks, 10 weeks gone and I thought he was going to give me a date to come back in next week and he told me there’s no heartbeat. Another yolk sac had collapsed and they couldn’t give me an answer to why it had happened...”
(p. 27)

Powerless Narratives

Within this master narrative, three subthemes were identified, expressed by participants as: *“You would think a Mum’s opinion matters”*, *“She knew best and you had to listen to her”* and *“I couldn’t have any control over what was going on around me”*. All three are now discussed below. What connected all three subthemes was the feeling of powerlessness, a lack of control and Pakistani women’s position as minority mothers.

“You would think a Mum’s opinion matters”

Women spoke about how at times their position as mothers was not taken seriously by healthcare professionals or their ability to be mothers was taken away from them. This also represented the loss of power that women experienced as mothers in the professional world. Sonia spoke about how mothers know their bodies better than professionals, yet despite this a mothers concerns about her pregnancy was not taken seriously.

“when you’re having pains and they say ‘oh, stay at home.’ In your head you’re thinking ‘yes, I better stay at home because they know better.’ But, I think, unfortunately, they don’t...because...the mother knows her body better than anybody else. So, if she’s had children before, she knows why she’s having pain. If she knows it’s a labour pain, then she knows it’s a labour pain. We listen to professionals thinking ‘oh...because they know. They know what they’re on about.’ If they say stay at home, they might say ‘oh, it’s okay. You’re not ready. Take a painkiller.’ So, in our head, we are vulnerable and we say ‘yes, okay. We will.’” (p. 19)

Similarly Fatima also spoke about how her concerns as a mother were undermined on several occasions when professionals were planning her baby’s discharge:

“...a couple of times I, by looking at him, I knew he wasn’t right and I quite openly say, ‘I’m not willing to take him home because he doesn’t look...’ But it was almost a case of ‘no,’ I didn’t have a choice in it. And you would think a Mum’s opinion matters” (p. 19)

Yasmin spoke about how she tried to gain back power in her interactions with professionals by re-establishing herself as the mother of her baby:

“Then I said to her ‘why are you talking like this with me?’. There were two of them so I said ‘I can give you the address of where she is as there’s nothing to hide, the baby is safe. And more importantly more than you, I am the mother, not you mum, me mum’ that’s what I said.” (p. 16)

Maryum who had experienced multiple losses spoke about her dream to be a “*breastfeeding mum*” when she successfully gave birth to her first baby and how this was not supported by the professionals around her. Maryum described how her right to be a “*breastfeeding mum*” was taken away from her, along with her baby by professionals at a time when she felt very exposed and vulnerable. This encounter re-traumatized Maryum. She described how she had been brought back to the ward following her c-section and she was finding it difficult to move. She explained that her baby had been left crying and hungry for seven hours despite her buzzing for help:

“...my boobs were so engorged, they were hurting...and she pushed him onto my stomach, which was already sore from the cutting up of it and it pushed down and it hurt my stomach, hurt my boobs, I cried so much and I said ‘I can’t do it’ and she goes ‘give me...you’ve got plenty there. It’s not like you’ve got nothing there.’ you know, like, proper rude and walked off with my baby to go feed him. And at that point, I didn’t want my baby taking away because I had...I’d lost my babies and I didn’t want my baby to be anywhere out of my sight. I was panicked, I was anxious. I didn’t want him to go anywhere where I couldn’t see him and that wasn’t respected.” (p. 26)

“She knew best and you had to listen to her”

All the women spoke about their experience of interacting with professionals and the professional world, they spoke about staff attitudes, feelings of powerlessness and behaviour which empowered or disempowered them. Zaara spoke about how difficult she found her interactions with her fertility Consultant:

“The consultant there, to say the least, had no interpersonal skills, no communication skills. She knew best and you had to listen to her. She was not interested in what my views were, what my opinion was, what my experience was. It was in black and white in front of

her, so she just wanted me to listen and that is very difficult for someone like myself. Firstly, from the profession and secondly, from the experiences that I've had...I felt really hard done by." (p. 4)

Fatima spoke about how she felt that her son was treated as “*beds and statistics*” and the emotional impact of this on her, she also spoke about how she was told she should be “grateful” for the care her baby received:

“Literally, got home and a couple of hours later he got serious again and I ended up taking him back to hospital. I literally, burst into tears and saying that you keep fobbing us off. It's all beds and statistics to you...one time when I took him in an ambulance, an ER nurse said I 'had to be grateful for the nurses looking after him,' so I lost it with her and I said, 'do you not get paid to do your job. You're not doing me a favour. It's your job’” (p. 10)

Women spoke about power in racialised terms. They attributed more power to professionals and Whiteness. Yasmin spoke about her experience of a White social worker:

“Then came another new White social worker, [social workers name] was her name, she must have come two or three times. The last time she came to see me she brought a huge statement with her before the baby was born and believe me she said ‘read it’ and I couldn’t so she said ‘give it I’ll read it and make you hear and what I’m saying in this statement is that the baby that passed away you don’t care about it...’ You tell me Romana, my baby passed away in 1997 and the baby was due in 2011 and the social worker sat down and says to me that ‘you don’t even care about that baby’. What can I do? Since the baby passed away its been 10, 11, 12, 13 years, what can I do? Shall I drub myself? Shall I cry? What shall I do? She goes ‘I feel as though you don’t even care about the baby’” (p. 12)

Some women also spoke about times when they experienced racist attitudes from staff and this influenced how safe they felt. Maryum described her experiences:

“this particular midwife was racist with us, I felt threatened by her. I didn’t feel my health and my well-being was being protected by her and nobody was there...they were happy to listen to what I said, but they wouldn’t take any action on it. So, yeah, I remember telling

my doctor, my own GP. She listened to what I said...but, again, nothing was fed back. Nothing was followed up” (p. 34)

Women also described times when professionals treated their babies as more than just “statistics” which helped them to develop a relationship with that professional. Fatima spoke about how her doctor affirmed her previous loss and recognised her, which she found helpful and normalising:

“...he actually got a chair, came up to me and sat next to me and talked about my baby. He wasn’t just another statistical figure that had died on their ward and it wasn’t a baby that had come and gone and end of story, move on with life. He specifically remembered him by his name and he mentioned that, ‘I still remember him till this day because he was the biggest baby on the ward and we weren’t able to do anything, we weren’t able to find out what it was.’ So, it was really nice to speak to him” (p. 18)

“I couldn’t have any control over what was going on around me”

All the women spoke about times when they had no choice or control over what happened. Shabana described that despite reservations from her husband, staff still decided to bring Shabana’s dead baby to her. Seeing her baby caused Shabana a lot of distress:

“They told my husband that they’re gonna bring the baby to us ‘we’re gonna bring the baby in’ and my husband wasn’t so keen about it. He didn’t want...for me to see it that way. But they did it anyway.” (p. 9)

Maryum spoke about how systems and professionals can give or take control from women and the subsequent impact on their wellbeing:

“...whenever I was, you know, going through a loss...I felt really like, I couldn’t have any control over what was going on around me and especially when I had that midwife called [midwives name] looking after me, who I thought was like lady from Misery. She was horrendous and really scary. I felt threatened and I felt so vulnerable” (p. 36)

At times when women felt they had no control or power in the system around them, they reported that the only option they had was to leave and get out of that system. In Maryum’s case that involved discharging herself from the hospital:

“You know. I didn’t stay there. I stayed there one day and the next day I discharged myself. I said ‘I’m not staying here’ and left” (p. 53)

Whereas for Yasmin it involved leaving the country altogether:

“Then when my second baby was due, I could see that they were putting up obstacles so what I did was after thinking a lot, I went to the clinics and got checked out and quietly booked a plane ticket and ran away to Pakistan. I had no other option, because...I couldn’t tolerate it. I couldn’t tolerate it as a mother” (p. 10)

Grief Narratives

Within this master narrative, three subthemes were identified, expressed by participants as: *“The Last Moments”*, *“It was just like echoing voices in the background”* and *“They say time heals it...it doesn’t”*. All three are now discussed below. Women’s grief narratives were influenced by the final moments with their babies, time and their individual grief reactions.

“The Last Moments”

All the women spoke about their final moments with their babies; this represented an important aspect of their bereavement experience. Women’s narratives suggested that the final moments with their baby had a significant impact on their grief and bereavement experience. Final moments that were experienced as negative had a significant impact on women’s health and wellbeing, Yasmin spoke about her final moment with her baby and what happened when she tried to embrace her baby for the last time:

“[the nurse] goes ‘you can’t touch it’, I just started crying, I think I went into shock that ‘what is this?’ I couldn’t even speak, so that I could have asked her ‘why?’ I couldn’t do anything, I couldn’t speak, I just cried and cried when she said ‘you can’t touch it’” (p. 20)

Not being able to embrace, touch or hold her baby for the final time had a significant impact on Yasmin. Similarly, Fatima spoke about seeing her baby buried and the impact that had on her:

“I saw...my first son being buried and it was one experience that I’ve regretted ever since. I shouldn’t have seen him literally being put into the ground. I know what a burial

is and I know what a cremation is as a theory, but to see it happen to someone you love, I think that was the worse mistake I ever made.” (p. 22)

In contrast positive final moments helped women to begin to come to terms with their loss. Maryum spoke about her final moment with her baby daughter as enlightening, particularly as she was able to see her daughter breathe and hold her warm body:

“Amina gave her last breath...on my chest. And I just remember.....with her last breath just.....kissing her good bye and promising her that we will meet again, inshaAllah. That was hard. But, I felt stronger this time because I felt...[tearfully] Allah has blessed me and I felt so thankful to Allah at that moment. I can't explain it. I just felt really...like I could feel Allah's 'Rahmat' [blessings] on me...I felt really enlightened. And I just felt 'I got to see my baby breathe. I got to see her move her head. I got to hold her warm body next to mine before it went cold.' And I was grateful. And thankful for those little things. I didn't feel angry. I didn't feel upset. I just felt...the most thankful I've ever felt.” (p. 16)

“It was just like echoing voices in the background”

Women described their reactions to the loss of their baby in unique and individual ways. Most of the women used metaphors as a way to describe their initial grief reactions. Zaara spoke about how she experienced grief when she went into early labour:

“I just went into a robocop mode and I said 'well...' I know a friend who had a stillbirth and she was early. She went into labour early as well and I was just recalling her experience and I said 'well, you're obviously going to have to deliver this baby,' and I was talking in the third person. I wasn't talking as if it was happening to me” (p. 7)

Distancing themselves from their experience allowed women to manage their grief and distress. Maryum also spoke about her grief response after she left hospital:

“I was in, like a zombie mode for two weeks. I remember...you won't believe this; I got my Eisa's teddy bear out, that I bought him and I remember the outfit and this coat that I'd bought for him and I put it all on the teddy bear and walked around like it was Eisa. I don't know why. It's like, almost like I'd reverted back to where I was 12 months or more plus before, you know when I'd gone agoraphobic. I didn't want to go out. I didn't want to look out of the windows. I didn't want to see anybody.” (p. 9)

Fatima also described her grief reactions, for her everything seemed to fade into the background and she spoke about “*voices echoing in the background*”. She spoke about hearing the same words over and over again:

“It’s just one of that mental state. Sometimes you’re switched on and you’re listening to everything they’re saying to you and other times it just feels like a broken record; people saying the same thing again and again and again.” (p. 21)

“They say time heals it...it doesn’t”

All the women spoke about how their bereavement was timeless, in the sense that it continued and endured. Alahnah spoke about how she would never be able to get over her grief despite having another daughter, the expression of emotion at this moment reflected how raw her experience still was:

“She would have been 16! [sighs] you know they say time heals it, it doesn’t [crying]” (p. 8)

Zaara also spoke about how the experience of infant mortality remains with the mother and influences her subsequent experiences:

“...you never get over your experiences, you never get over that grief. And that experience will always taint your experience and it always taints my experience to the extent that I’m always telling other people my experience to make sure that they know what to look for.” (p. 22)

Women also spoke about what it means to be a “*grieving mum*” and though society may impose a timescale on grief, in their experience time is irrelevant:

“You’re a grieving mum for the rest of your life, you don’t get over it in a couple of years.” (Alahnah, p. 30)

Sonia like the rest of the women expressed how her bond with her son will always continue:

“I’ll never, ever, ever forget Michael. He will always be in my heart” (p. 18)

Transformative Narratives

Within this master narrative, three subthemes were identified, expressed as: *“I was Alhamdulillah very fortunate that I had my family around me”*, *“I’m not who I was eight, nine years ago”* and *“We were all bereaved mums”*. All three are now discussed below. Transformative narratives reflected how infant mortality changed the women and what helped them to heal and transform.

“I was Alhamdulillah very fortunate that I had my family around me”

The role of family support was evident in all the women’s narratives. Family support included their husband, their parents, extended family, their children and friends. Zaara spoke about the support she received from her family:

“I used to have lots of support from family and friends that would bring my meals round and my husband would finish work and he’d look after me. I was really treated really well and so, I didn’t have any qualms about my treatment, family wise” (p. 6)

Fatima spoke about how she was supported by her husband to begin to continue with her life as she wanted to get back into education:

“So, I came home and had a word with my husband and he was like, ‘well, if you want to go back I will support you and don’t worry about it.’ (p. 5)

Women also described how family helped them through the aftermath of the death such as with funeral arrangements. Alahnah described how her brother helped her with the funeral arrangements:

“my brother, he took over everything, he organised the burial, he organised the Janaazah [Islamic funeral]” (p. 13)

Sonia described the invaluable role of a husband in supporting a woman to live through her loss and to remain strong:

“My husband was being so good, maashAllah...I give him so much credit for being so strong for me...he was like a rock. Without my husband I don’t even think I would be sat

here now. I don't know what would have happened to me. I don't know what I would have done to myself. He was so supportive" (p. 15)

However women also described how not having family support could impact on their bereavement experience. Alahnah spoke about how she is still unable to talk to her husband about the death of their daughter:

"I can't say in front of him. I can't say 'oh remember [husband's name] when we had Munna and this, this and this happened?' I can't, I can't talk to him" (14)

Similarly Maryum spoke about how her difficult relationship with her husband impacted on her bereavement experience: She described how her husband's inability to acknowledge her grief and loss affected her:

"my husband, the fact that he didn't care, the fact that: 'it's all right, we've got him. You know, if it's meant to be, it will happen, if not it doesn't matter.' You know, I felt really angry at him. It just brought up a lot of unresolved issues that I had with him and I just felt like I was on my own" (p. 27)

"I'm not who I was eight, nine years ago"

Women spoke about how infant mortality has transformed their identity and their sense of self. Fatima described how her losses have made her a stronger person:

"I mean there have been ups and downs in between but I think that overall, losing my two sons has made me stronger. I'm not who I was eight, nine years ago and I think, as a Muslim, my belief is Allah only tests those who He thinks will be able to get through it. He gives us the patience and guides us" (p. 13)

Sonia also spoke about how the loss of her son Michael has made her a stronger woman:

"I feel really happy about and thank Michael for making your Mum a stronger person with what I've been through...still going through" (p. 18)

Sonia also reflected on how she would have acted differently in the past when she first felt something was not right with Michael. Sonia explained that her loss has helped her find her voice:

“I think.....it was only that time when I was carrying Michael and...I rang the hospital, that’s when I was scared to say anything and when...they said 'stay at home.' That's the only time when I felt 'I wish... Looking back now, I wish I'd have gone in. I wish I had said to them 'excuse me. I know,' you know, and spoke up a bit more, but I didn't...and now I think I become a stronger person, getting involved with these groups, like HOPE. I think that’s made us a stronger person to do things and complain and speak up. And now, I think, God forbid, if anything happened to anybody, I'd probably be the first person to complain. And I will do because, normally, you brush it under the carpet and say 'it doesn't matter, leave it.' But, now, being involved with these organisations and these groups, we would probably do things differently now” (p. 20)

Zaara also spoke about becoming an empowered woman through her experiences, more confident and more involved in her own care:

“I think, obviously, I’ve learnt a lot from what’s happened in the past and for mistakes not to be repeated and I feel more comfortable and confident in talking to the staff and telling them what I want doing instead of just leaving it on them to advise me. And I think I’ve become more empowered, sadly, through what I’ve been through, to organise my care” (p. 14)

Women spoke about how their loss had motivated them to bring about change, Sonia reflected on how her loss had been a motivation to do something different:

“But, since then, Michael's....he's left me...he's opened so many doors for me. I've done so many things after Michael...And that is only because...no disrespect to Michael but, everybody always say that 'if Michael was here, you would have just been carrying on as normal, doing your normal duties and everything. But, look how much Michael has left you behind. Look how much he has made you do.” (p. 17)

Zaara also spoke about becoming “proactive” after her loss:

“I’ve tried to be as proactive as I can in respect of that. The latest offshoot of that is I’ve been invited to become a board member of [Organisations name]. So, I’m a board of trustee member there so, alhamdulillah, I’m just trying to do as much as I can and, perhaps, had I not been through my experience, I wouldn’t have been so involved, so...I see that as a bit of a silver lining and, inevitably, my overall goal is that I pray and I wish that nobody has to go through what I’ve been through” (p. 16)

“We were all bereaved mums”

Zaara spoke about how her understanding of infant mortality transformed when she realised that her experience wasn’t “rare”. Zaara spoke about the power of the dominant discourse of pregnancy which is based on “normality” and good birth outcomes.

“I never suspected...I’d never known anyone...and I didn’t think it could happen to me. I just thought, you fall pregnant, you have a baby...very naïve, looking back now, but that’s what, from my experiences and, from what I’ve seen, it’s very rare, very rare. And, now, I understand that it isn’t rare, it’s just, it’s not spoken about. And I think a lot of women go through some type of tragedy, but because of how it’s dealt with in the hospital and then how it’s dealt within the community, it’s never spoken about, so you only hear the good stories and the successful ones where you see the baby.” (p. 17)

As a result most of the women spoke about how they found the opportunity to be around and share with other bereaved women a liberating experience. Sonia spoke about her experience of being involved in a group for bereaved women:

“So, I feel groups like this help a lot. They help parents, hopefully become stronger and hopefully, have somewhere to go. Speak to somebody. Link them to other parents who have been through the same...we met people that we have never, ever before seen in our lives and become quite close, become friends. And we try to support each other and Ghazala and Katie were really, really good with us. They tried to help us in all ways. Now we are still in touch.” (p. 17)

Fatima spoke about how a group for bereaved women helped her to begin to process her grief and live on, particularly as she did not prefer to speak to her family:

“So, then Ghazala came and I talked to her about it and as the research continued, I met other mums. It started getting easier that I didn’t have to talk to family because I thought the family were trying to help me to get over it for my kids sake, so it was one thing that I didn’t want to constantly be dragging them down with me. I’d have bad nights, talk to my husband, that kind of thing, but I started to get over it.” (p. 13)

Zaara also described the impact meeting other bereaved mothers had on her, such as it reduced her sense of being alone and gave her a safe place to grieve:

“I was in contact with HOPE group and I was able to share my experiences with Ghazala and Katie and that has given me an opportunity to really grieve in a sense and get some informal counselling in a way because I was with alike women, to speak to them about their experiences and that I am not alone, that I am not a freak.... when I go to groups, such as HOPE, and I meet the other ladies, it's nice because I don't feel lonely. Although their experience is something different, I feel an attachment, I feel a bond” (p. 24)

Coming together as bereaved mothers helped women take a stand against some of the injustices that they had experienced. Both Fatima and Yasmin spoke about taking a stand:

“It opened up many doors and it gave me that little push I needed to make a stand. So, we had meetings with nurses, doctors and conferences...and it gave me the opportunity to say what I was feeling, knowing that it was actually being heard. It's not just something I've let off my chest and 'hey, over and done.' Whether it's one per cent difference or not, that's beside the point, but at least I knew that people were listening. So, it was Ghazala's research that gave me that opportunity and I will always remember that” (Fatima, p. 28)

“I know it's happening to other mothers too and I want us all to stand together for the truth” (Yasmin, p. 27)

Sense-Making

Across all the women’s accounts of infant mortality sense-making was identified as a master narrative. Three subthemes were identified which influenced women’s sense-making: stories of blame, noticing inconsistencies and religion.

Stories of Blame

Women described a number of different stories of blame which included medical, cultural and self-critical stories which located the blame for infant mortality within minority mothers. Alahnah described the profound impact a comment made by her doctor had on her understanding of why her daughter Munna was born with a life-limiting condition:

“In a way you know when Dr D said to me that, he didn’t put it down as ‘it’s my fault because we’re cousins’, but he said because we’re cousins ‘its genetic’. I don’t know if you’re gonna understand what I’m going to say next, but I’ve always thought it’s my fault cause I’m his cousin.” (p.25)

Medical narratives are very powerful and dominated women’s understanding of the cause of their loss. In addition the stories told by doctors, geneticists and fertility consultants become the ones against which others are judged as true or false. Yasmin demonstrated this when she compared her “*testimony*” to those provided by professionals:

“I mean after 10 years why has their testimony changed? For 10 years my testimony has been the same, it was the same then and it is the same now. I haven’t changed my testimony then why have the doctors changed their testimony?...How do you know? How can you blame someone? Did you see me do it?” (p. 8).

Fatima also spoke about the impact of blame on her role as a mother:

“Throughout all my journey I had run ins with doctors, nurses. One senior nurse had made a comment like, ‘you need to get used to it because that’s the way he is now’ and that was quite hurtful because it almost made it sound like I didn’t want to take a disabled child home” (p. 10)

Alahnah also spoke about cultural stories of blame and how they influenced her relationship with her baby, she said:

“People from my background they say you know ‘if you’ve done something wrong Allah Taala punishes the person you love dearly’ and that’s what I thought, that ‘I must have done something wrong that my Allah is punishing me’, that’s what I thought and that’s why I wanted to be there for her.” (p. 25)

These stories of blame result in a strong sense of guilt and personal responsibility, Alahnah clearly illustrated this in the quote above. Bereaved Pakistani women can then begin to internalise these stories and construct their own stories of blame. All seven women often criticised themselves and wondered if there was anything that they could have done differently to prevent the death of their baby. A striking feature of Pakistani mothers narratives were their attempts to pinpoint their specific fault:

“I left work and went straight from there to my baby’s graveyard...I went and sat with him for 45 minutes and I cried and I talked to him ‘aww baby, tell me what happened to you’. I don’t know ‘when you went from me this wasn’t there then how did it happen, how did you get burnt?’ I just saw his face, I didn’t see the rest of his body whether his hands were burnt or not. Now when I think back I wish I had looked.” (Yasmin, p. 13)

“You know in my head I think ‘If I hadn’t taken that half hour to decide if I wanted it done or not, she probably wouldn’t have had a collapsed lung or stopped breathing’.” (Alahnah, p.22)

The uncertainty around the death of their baby meant that women were often left to wonder *“where does the blame lie?”* This was particularly in relation to not recognising warning signs; Zaara spoke about this when she said:

“I hadn’t a clue. Considering what I do for a living and what my ability is, Alhamdulillah, I would have thought I would have known but, again, is it down to naivety, stupidity...ignorance or...I don’t know, I don’t know. Where does the blame lie? Does it lie with me because I didn’t research it, I didn’t have the knowledge or was it because the providers hadn’t given me that knowledge? Or did they assume that I had that knowledge or is that just normal for everybody?” (p. 7)

Noticing Inconsistencies

All the women spoke about noticing inconsistencies in the care they received, in the stories they were told, in the advice they were given and in what they witnessed. These inconsistencies increased their sense of uncertainty and mistrust and affected their confidence. Zaara spoke about her experience of receiving contradictory diagnoses and the impact it had on her ability to trust professionals and services:

“I dismissed what the consultant said and I said 'well, I've been to [name of hospital]. They said it was a miscarriage and now you're telling me it's an ectopic and it's a ruptured ectopic and it's very serious and if you don't operate on me, I will die? In those stark terms, you've just explained that to me. That is very hard for me to digest' because I was a bit reluctant when dealing with doctors, because of the two miscarriages, the blasé attitude of 'oh, it's so common, you know. Just get on with it. It happens.' So, because the trust had broken down, I was very sceptical of the consultant.” (p. 3)

Fatima also discussed how she witnessed inconsistent practice which distressed her and worried her about her baby. Fatima described a time when a doctor had tried to unsuccessfully cannulate her son a number of times which caused her baby immense pain. A week later she saw another doctor try to cannulate her son but before she tried she applied a cream:

“I lost it with her. I go, 'what are you doing?' and she says, 'I'm going to put this on so he doesn't feel the actual needle going in.' I go, 'is that standard or what?' she goes, 'what do you mean?' and she could tell I was heading somewhere and she started covering her tracks and I was like, 'well, that day, why didn't they do it?'” (p.19)

Fatima also narrated an instance in which she was given conflicting messages from her baby's treatment team:

“I rang up in the morning and apparently, his oxygen hadn't been goodhe'd had a hard night or whatever. A couple of hours later I got a call saying that, 'you can come and take him.' I was like, 'what do you mean? You said in the morning, he wasn't fine.' So, when I went in...I argued with, 'why, in the morning you tell me he's not well and now, all of a sudden, he's all right, I can take him home. I don't want to take him home.' But it was a case of, 'no, you're going to have to. Doctors have agreed and this and that. It didn't set right in my head, like what you said to me, he wasn't right. He wasn't well through the night, so why...? That was when I had the big argument with them.” (p. 27)

Inconsistent communication and conflicting messages from staff led to additional distress as it provided neither certainty nor assurance. Ambiguous or inconsistent communication could also leave mothers feeling ill-informed or unprepared. Noticing and feeling able to question inconsistencies seemed to be an important part of women's narratives. However this also

suggested that women were left with a lot of unanswered questions and that they were still actively trying to make sense of their experience. Zaara's narrative was replete with inconsistent experiences; she made sense of this through the act of questioning:

"I know...her lungs hadn't developed....she wasn't able to breathe by herself and, again, there was a contradiction because how was she then born alive if she wasn't able to breathe? How does your heart beat if you can't breathe?" (p. 10)

"The first question was 'why...how come I went into premature labour? When there were no real signs for it in the first place?'" (p. 10)

"But, why had I gone into premature labour? Why did my waters break? Why? What was wrong?" (p.12)

"I know they said that there wasn't enough room for her to develop or grow, which was a contradiction because I had been to a scan and they said that she was fine; that she was growing according to their statistics and their graphs. So, it just didn't make sense. So, I wasn't really given any clear answers" (p. 12)

In addition for women questioning contradictory and conflicting messages and practices was an attempt to challenge the dominant discourse that medicine is a perfect science, Maryum highlighted that in her experience it was imperfect:

"I got examined and the doctor said 'ooh, your cervix is fine. It's closed... You're not going into labour. Don't worry about it.' And I was having shooting pain down inner groin, inside of my one leg and I was saying 'I've got a pain in my back.' They should have known that these are symptoms to follow up and send me to Early Pregnancy Assessment Unit and get a scan, but they didn't do anything like that. They didn't do any blood tests on me. They didn't do no urine test on me. They just said 'oh, you're fine. You've got pelvic dysfunction. That's all it is. You might be suffering from that... And I just couldn't believe what they were saying and, anyway, I left and then it was Tuesday, Monday night after that I actually started haemorrhaging and losing baby. So, two days before they said I was fine, two days later and that happens." (p. 34)

Religion

Pakistani women spoke about the comfort and “solace” they found in their faith and religion during moments of uncertainty and following their loss. Their faith provided them with a sense of meaning and hope during times of uncertainty. At these times all the women spoke about “leaving it in Allah’s hands” as a way to cope with their intense feelings. For Sonia “leaving in in Allah’s hands” allowed her to connect with her baby and to spend time with him:

“I think Allah helped me all the way through. Tried to make me stronger and just sit and pray and read...first, I just thought 'oh, my God, what’s happened?’ And then, when weeks went past, I used to think 'leave it in Allah's Hands and just take every day as it comes. Enjoy yourself. Spend time with Michael.’ We knew, at the end of the day, we weren’t going to have Michael for a long time, but we used to think 'only Allah will help us. Just take every day as it comes' and, maashAllah, Allah did give us all that time. Allah gave us three months with Michael, you know, to us is a long time. We could have had Michael for a few weeks. We could have had him for days and Michael could have gone. But we believed in Allah to say 'Allah will help us’” (p. 21)

Religion provided women with a counter-narrative that was encouraging and empowering rather than the dominant medical discourse which was experienced as crushing. In addition “leaving it in Allah’s hands” allowed Pakistani women to resist the stories of blame that located the control, responsibility and outcome of birth within themselves. Yasmin eloquently illustrates this resistance:

“It’s Allah’s possession and Allah has taken him. Life and death is in Allah’s hands, no one else has any control” (p. 5)

Similarly following the bereavement, religion provided them with comfort and relief. Zaara spoke about a conversation she had with another bereaved Pakistani woman which helped her find “relief” in her religion:

“she said 'you know, it will get easy. You’ve just got to keep your faith and it’s at those times when you do question your faith and you think 'why, why me, why?’ you know, Astaghfirullah [may Allah forgive me], you ask these questions, which you shouldn’t ask, but because you’re going through this emotional turmoil and you begin to question

everything. But with the same token you find a great solace in your religion.' And, also, I did find that as well. I found relief.” (p. 11)

Women also spoke about the knowledge that they will meet their deceased babies in heaven as one way in which they could hold on to hope and the wish that they would meet their baby again. In Islam it is believed that children who have died await their parents at the gate of Paradise (Arshad, Horsfall, & Yasin, 2004). Shabana spoke about this:

“family would come, they’d come and see me and they’d say to me ‘oh you know, you got two, kids waiting for you in paradise now, they’ll be waiting at the doors of heaven’. ‘You know, you should be grateful, you should be happy that, you know, you’ve got them waiting for you’” (p.14)

Fatima also spoke about how the knowledge that she will meet her babies in Paradise helped her to come to terms with her loss:

“As a Muslim, my belief is Allah only tests those who He thinks will be able to get through it. He gives us the patience and guides us and I think, if anything, I am blessed to have two children waiting for me in Heaven and I’ve just accepted it.” (p.13)

Women also spoke about how religion and Allah made them stronger and supported them through their grief. Alahnah spoke about what happened at her daughter’s funeral:

“So they put her outside in the garden [gasps] but you know what? Allah gave me so much strength that I didn't even cry on top of her coffin, all I was doing was looking at her,” (p.13)

Alahnah was surprised by her patience and resilience at her daughter’s funeral and that this was made possible because of her belief in Allah. Maryum also spoke about how Allah has helped her through her bereavement:

“I found that I’ve been tested quite a bit in my life and in different episodes in my life and I’ve found that Allah has always been present and I’ve always witnessed miracles myself...quite literally, you know, that I know that Allah exists because I’ve seen it happen so many times in my life...I mean, I could write a book about my life, I really could, with

the kind of stuff I've gone through. But, the one thing that's helped me every time I've hit the rock bottom stage is Allah Himself.” (p. 40)

At times of difficulty Pakistani women maintained or rekindled their connection with Allah. This connection meant that women spoke about receiving “*signs*” from Allah that they would be rewarded for their patience and suffering. Maryum spoke about “*signs*” a number of times in her narrative, she spoke about a time when community midwives turned up at her door asking to weigh her dead baby as a “*sign*” from Allah, she said:

“Well I feel like that day, that Friday, when the midwives turned up, I'd asked that question about why it's happened to me. Am I ever going to be a mother and please show me a sign and then they turned up and asked me where's my baby, so for me it was like a sign to say 'this will happen. They are going to come to your door.' You know, so that was an answer for me and, even though it was a mistake for them, I saw them as little messengers for me.” (p. 46)

Alahnah also narrated a conversation that unfolded when she told her husband she was pregnant following their loss. Alahnah's husband was worried about the subsequent pregnancy, but Alahnah explained to him that:

“but you won't go through that again, because I know my Allah Taala's going to give me a healthy baby', I go 'that was a test, we've done it and I don't know if we've passed or whatever but this time I know for a fact that its going to be a girl and that its going to be healthy because I know', he goes 'how do you know?' I go 'because D told me that he had a dream and I believe...’” (p. 17)

Alahnah's son had spoken to her about a dream in which he had seen his sister, for Alahnah this had been a powerful “*sign*” from Allah that he would bless her with a daughter. Lastly four of the women spoke about a religious charity which helped them to process and voice their grief, namely Children of Jannah. Zaara was sent information about the charity from Maryum:

“I was sent a link from Maryum called 'Children of Jannah' and I downloaded the booklet and that was a really nice read. It was lovely. That gave me some comfort, reading that.” (p. 11)

Fatima also spoke about her involvement with the charity and the impact it had on her grief:

“She mentioned Children of Jannah, the only Islamic charity in the UK dealing with child bereavement. I became a Facebook member with them and I started writing on the Facebook page my feelings, reading other mums and I started to find that started to help me and the process of the bereavement” (p. 13)

Meeting Our Needs

Another master narrative in women’s accounts of loss was expressed as *“meeting our needs”*. Within this the women identified three ways in which their needs could have been better met such as bereavement support, practical support and voice and visibility, as well as areas for further development. Giving feedback to services and suggesting changes was a key part of each woman’s narrative.

Bereavement Support

All seven women reported that they had been offered no bereavement, emotional or psychological support from services following the loss of their baby:

“And even afterwards as well I didn’t get no support or anything. No bereavement support, nothing” (Shabana, p. 5)

“And grief is grief. People deal with it very differently. But they need to grieve and they need to be given that support and I think that’s where it was lacking in the hospitals” (Zaara, p. 15)

“we came back after seven weeks abroad, came back here. I saw one letter from the hospital saying that ‘we are sorry for what happened and if you need us you know where we are.’ Nothing more than that. I didn’t get offered any support. I didn’t get offered any check up after that; health visitor, doctor, nothing at all. It was just chapter closed for them” (Fatima, p. 5)

“Non existent. It was non-existent and I didn’t get any support. I feel the midwife didn’t come to the house to talk about my options for bereavement support or counselling support or any” (Maryum, p. 44)

However women also described what sort of bereavement support they would have liked from services following their loss. Zaara described how bereavement support should be introduced to women:

“I remember them giving me a pack of leaflets. Who's going to read leaflets when you're in that state? And so perhaps the help was in that pack and I was told afterwards there were numbers I could ring etcetera. So, I was able to ring up a stranger and talk to them. I just thought 'yes, that's really appealing after what you've been through, to just ring up a stranger and talk to them.' There should have been somebody there at the hospital to even provide the basic foundation for me to then get the comfort in, perhaps, approaching someone” (p. 10)

Meeting someone in hospital would have allowed women to feel safe and confident in approaching someone. However women also spoke about what bereavement support should look like in the hospital immediately after the loss. Maryum described her experience of being in hospital at the time of her daughter's funeral:

“That was hard because I was in the hospital the whole time that was happening and nobody was there with me. It would have been nice if somebody just came and sat with me. I was in a room on my own and I just remember looking at those four walls Romana and I'm thinking [tearfully] 'my baby's going to be in the ground right now.'....She should have been in my arms. She should have been in a cot and not in the ground and all these thoughts were going through my head and...I didn't need somebody to talk to...I just needed somebody to sit there and just be there with me and...just to...I don't know...it might sound stupid, but not to do anything else...just take my mind off what was going on and that didn't happen. So, that was lacking” (p. 18)

Zaara spoke about how important it is for bereavement support to be a part of the core training of professionals and described some of the attributes required:

“It's not a lot. It's just about being compassionate, about using common sense. It's about being human,, just to show you're a bit human, that simple touch or 'would you like something? Is there anything that I can do?' or simple words, 'I'm very sorry for your

loss,' instead of ignoring all of that,...So, it's just small things that can ease the process, not diminish it, but ease it, that's all you ask for" (p. 16)

Women particularly spoke about the need for psychological support, counselling and chaplaincy following a loss:

"I wasn't offered any sort of counselling or anyone from....Chaplaincy or the Mosque or anybody from the hospital to come and perhaps talk to me or sit with me and it was very lonely" (Zaara, p. 9)

Practical Support

Women in the sample described a range of practical support that could have assisted them during their loss and bereavement such as language support, access to services and information, antenatal classes for women who have lost before and support around leaving hospital.

The women described language support as very important particularly at times when professionals were breaking bad news to them. At these times participants were either not provided with interpreters for their partners or felt that the language support provided was not appropriate:

"When I was in hospital giving birth, I had to translate to my husband what they were telling me and the worst part is when you're trying to come to terms with what they are telling you yourself; 'your baby's dying, not going to survive' and you're having to translate that. It's the worse thing ever" (Maryum., p. 50)

"The two times we have had interpreters. As soon as the interpreter finished...I used to cringe during the interpreting because they weren't explaining things better. Do you know, they had no medical knowledge and I think I could have done a better job...So, they need better interpreters, definitely" (Fatima, p. 21)

Women also spoke about the importance of having access to information and services in order to make an informed decision. Maryum described how she felt she did not have access to all the information:

“They didn’t tell me about the injection I could have for pain. They didn’t tell me about other options for pain relief. They didn’t go through any of that...the information was lacking in what they told me. A lot.” (p. 7)

Women also felt that they would have benefited in subsequent pregnancies from antenatal classes that were specifically tailored for women who had experienced infant loss. Maryum said:

“what I would have liked is an antenatal class that would have been more specifically around women who have lost before. I didn’t have that. I actually ended up accessing Haamla...which was good. But, again, I felt like I couldn’t speak about my true feelings because there were women in there who were pregnant for the first time and I got told off by one of the midwives...I felt like it was a telling off. That, you know, ‘please appreciate that there are women here...who have never had a bad experience and I know you’re talking about what happened, but you might be scaring off other women. Because you can have these symptoms and it could mean nothing. It just depends on your history and blah, blah, blah.’” (p. 24)

And Zaara spoke about her experience of antenatal classes and how they were based on discourses of “normal” pregnancy:

“I went to a programme called ‘Birth and Beyond’ that’s been set up for ladies who are first time pregnant and my midwife thought that maybe I would benefit from it and I thought, ‘okay. I will attend’ because I wanted to know. And it was just about the perfect pregnancy. Nothing about what warning signs there should be. At the first session, they asked us what our expectations were of the six week course and I said that ‘I would like to learn first aid on a baby. What if you deliver early or when you’ve taken a baby home. Just basic first aid.’ It wasn’t canvassed. All it was ‘we’ve just built nice, pretty boxes and how you would emotionally deal with your emotions when you’re pregnant and afterwards.’ It was very, very fluffy and light” (p. 20)

Women also spoke about practical support that would have helped deal with the emotional impact of leaving hospital without a baby, such as being accompanied by a nurse or midwife and not being taken through a delivery suite. Shabana said:

“you know the hardest thing for me is to when I was okay and they discharged me, I didn’t feel like going home. I was just so so so stressed out and upset that I was going home empty handed, and that was the hardest thing to get out of the hospital with nothing in your arm, nothing. You know, nothing to show for it, nothing in your arms, it was just, you know, emptiness. You know I felt emptiness and no midwife, no nurses, nothing came to support me in any way. They didn’t come downstairs with me like normally how you know midwives they come when you’ve had a baby” (p. 5)

And Maryum described her experience of having to walk through the delivery suite after losing her son:

“I remember...coming out of the ward and getting into the lift and absolutely dreading it because there was no separate entrance. I know now, I was at [Hospital name], there is a separate alley, there is a separate entrance, but we wasn’t shown it. We had to walk straight back through delivery, back through delivery suite” (p. 9)

Voice and Visibility

Women felt that having a voice, feeling empowered and being visible in systems was important in helping them heal from their loss. Yasmin spoke about how important it is for the stories of bereaved women to be heard and that they should be given an opportunity to voice their experiences:

“this should come on the TV, it should be on the radio, however many women there are who are honest but helpless, who haven’t done anything wrong, they should come and speak their own truth. They should fight for their truth, they should break the law of social workers, only with honesty and truthfulness. Any mother who hasn’t done anything wrong...should come and speak the truth...they should be given a chance, they should be given an opportunity, they should be given time” (p. 17)

Similarly Shabana was able to express how her experience ought to have been and what bereaved mothers deserve from services. Shabana powerfully articulates the need for bereaved Pakistani mothers to be acknowledged and supported when leaving hospital alone and empty:

“I was going home empty handed, and...They didn’t come downstairs with me like normally how you know midwives they come when you’ve had a baby and they come all

the way downstairs to your car, and they'll put the baby in the car and you know in the car with you. You know and why don't they do that to them mothers... that have lost their baby? Why don't they walk them down? You know, show them a little bit of support and comfort them...you know. That is in their job as well to look after those women as well. And I didn't get that" (p. 5)

Women spoke about how being supported by professionals in having their voice heard allowed the memory of their baby to remain alive. Sonia described her experience:

"Dr O invited me to come and speak at a conference...in 2010. I was like 'I can't speak in front of people. How many people am I going to speak in front of?' About hundreds. He said 'I want you to speak about your experiences.' So, I agreed. I went. And it went really, really well. And since then, there's always been opportunities for me to go and speak about my experience at conferences in front of consultants, nurses, midwives, different organisations that are there. For me to go talk about my Michael. Michael always lives on because Dr O's always done something for me to go and speak about, I think, which is making me a stronger person and I feel I can support other people and help them" (p. 17)

All the women spoke about the benefits of sharing their story and the importance of being heard. Women voiced their experiences in a number of ways such as in the media, on TV, in newspapers and through research.

REFLEXIVITY

Continuing my Reflexive Account

During the course of the interviews, I learnt a great deal. Sometimes I found the conversations upsetting, sometimes difficult, but always compelling. From the moment I first met one of the women and all the way up to writing this thesis, I was drawn into seeing grief, loss, motherhood, relationships, the professional world and society in a new and different way.

In the Interviews

Interviews become socio-political and psychosocial spaces, for breaking the silence and for unmasking the hidden. I felt that talking about their loss in the interviews was another way in which the women kept the memories of their babies alive. I had anticipated that the interviews would be difficult but I had not pictured what that might look like for me.

After four interviews I saw myself frozen like a rabbit caught in the headlights. What was this research project in the face of the experiences of the women, bleeding uncontrollably, left for hours on end soiled in the middle of a hospital corridor, babies dead with unknown causes, their dignity shattered into a million pieces? What was this pain, this emptiness, this numbness that I carried with me for days after each interview? What was it called? Why couldn't I place exactly what I was feeling into words? Why was it that when I was prompted to talk about race, gender, religion or infant loss I would get angry, tearful even restless? Who was I angry with, what was I restless about?

I was especially disturbed and challenged by those accounts that revealed racist experiences that the women had encountered in services and with professionals. I reflected on my experiences as a BME researcher engaging with such experiences and what it brought up for me. My own experiences of feeling silenced, not being believed and not being valued within a powerful system were particularly pertinent at this time. However I was offered de-brief sessions with a member of the Clinical Psychology Faculty which allowed me to process this. Initially I had been unsure about whether any member of the Faculty would be able to understand the impact racism had on me and the women and this apprehensiveness both puzzled and disturbed me. I wondered whether my experience reflected how the women must have felt when experiencing racism in powerful systems; they too must have grappled with questions such as '*Who can I speak to?*', '*Who is it safe to speak to?*' and '*Will they understand me?*'

Analysing the women's narratives

Every time I opened the folder titled '*analysis*', I would immediately close it down. I knew what I wanted to say, I just didn't know how to say it. The data was supporting what I

think I had known for a long time but yet was never able to articulate: that the experience of bereavement is sometimes not as it is reflected in models of grief, that Pakistani women resist many of the discourses constructed by professionals and Maternity services, that empowerment is about voice and subsequent change and that society, systems, professionals and even family can exacerbate grief or compel those affected to remain in grief.

Crisis of representation

I faced many dilemmas when beginning to think about representing the bereavement experiences of the women I had interviewed. Questions like whose reality am I representing? Can these themes do justice to their experience? Who am I to decide what is represented? How can I represent their experience fairly? I think the horror I felt about turning the tragedy that each woman had experienced in to a research project was overwhelming.

I also faced many questions about representation, questions like “*how do you know this actually happened to the women?*” and “*how can you say that what the women told you is the truth?*” It was at times like these that I was challenged; would I stick to what I had originally set out to do which was to present the experience of infant loss from the standpoint of marginalised women or would I change my perspective to suit the academic system in which I was situated? As a result I was plagued by contradictory emotions and conflicting loyalties; should I remain loyal to the women who shared their most intimate stories and the method which allowed me to privilege their voices or bow to important actors in the powerful academic institution that will decide whether my writing is good enough? Through discussions and the process of doing this research I realised that both could be achieved. I learnt to represent the narratives of the women in a way that systems and professionals could hear what was being said. I was also able to justify my decision to represent women a certain way by grounding it within the research paradigm and methods I had chosen.

Although I make no claims in the end that my analysis was objective or neutral, I feel I did not ‘*take sides*’ at the expense of a thorough and systematic analysis of the data. I was able to resolve the dilemmas that I faced in relation to neutrality, advocacy and researcher subjectivity, through an understanding of Feminist Objectivity, which “*means quite simply situated knowledges*” (Haraway, 1988, p. 581). By keeping in mind Bhavnani (1993) and Haraway’s (1988) conceptualisation of Feminist Objectivity, I was able to situate the knowledge I was producing by embedding it in the words of the women themselves.

DISCUSSION

One of the key recommendations made by the National Perinatal Epidemiology Unit has been around the importance of “*listening and talking to women*” following loss. Redshaw and Alderdice (2015) suggest that hearing from women in their own words about their experience of pregnancy, childbirth and the postnatal period is an important way of learning about their care from their point of view. In this sense this study was one of the first to “*listen*” to Pakistani women about their experience of infant mortality and therefore provides novel insights into their experience of bereavement. Evidence has consistently suggested that the experience of minority ethnic women is different in maternity services compared to the general population and that they are more likely to report negative encounters with professionals (Jomeen & Redshaw, 2013; Redshaw & Henderson, 2015).

This study confirms that the death of a baby can have a profound impact on the mother and that women can experience mental health difficulties such as depression and anxiety (Boyle, 1997). As documented in the general literature, following the loss Pakistani women interviewed often reported intense and conflicting emotions as well as a range of grief reactions such as sadness, shock, anxiety, anger and guilt (Nordlund et al., 2012). However feelings of guilt and self-blame were exacerbated in these women due to their position as not only mothers, but Asian mothers. These intense feelings of guilt and self-blame were linked to the dominant genetic and biological discourses around infant mortality (Darr, 2009; Shaw & Raz, 2015).

Furthermore, though evidence suggests that generally women report feeling confident in staff, feeling listened to and having access to support from professionals following the loss of their baby (Redshaw et al., 2014), women in this study often reported negative encounters with professionals. In addition women in the general population report having access to counselling and bereavement midwives when needed (Redshaw et al., 2014), in contrast all seven women in this study reported not having access to any bereavement support. This study confirms findings in the literature that some women report not being informed or involved in decision making at times during labour and birth when their babies did not survive. As a result women can feel both empowered and powerless when interacting with health professionals (Lundqvist, Nilstun, & Dykes, 2002). In addition apart from feelings of uncertainty, grief and powerlessness, women in this study also illustrated the transformative potential of loss and the importance of religion in helping them cope. The role of religion was particularly pertinent in the narratives of Pakistani women in contrast to women in the general population.

Women interviewed for the study suggested a number of ways in which services could improve to better meet their needs confirming recommendations in national guidelines and

Toolkits (DoH, 2009; NICE, 2014, 2015). This included the provision of bereavement support services and specialist language support (NICE, 2014, 2015) for Pakistani women. In addition as recommended by the BLISS and SANDS Toolkit (DoH, 2009) women emphasised the importance of encouraging and supporting women to engage in decision making, providing psychological support and regular communication with professionals.

Six master narratives were elicited from the data: uncertain narratives, powerless narratives, grief narratives, transformative narratives, sense-making and “*meeting our needs*”. These findings will be examined in relation to the wider literature and the research questions. The strengths and limitations of the study will be considered and suggestions made for future research. Finally clinical implications for services will be discussed as well as recommendations for practice.

Bereavement experiences of Pakistani women

Pakistani women’s bereavement experiences were both different and similar to dominant understandings of grief processes in the current literature on bereavement. The master narratives of uncertainty, powerlessness, grief and transformation offer insight into their bereavement experience and participants demonstrated the interconnection between these narratives. Feeling powerless and uncertain exacerbated their grief whereas feeling empowered and supported to bring about change helped their grief to heal.

Pakistani women in this study experienced grief as overwhelming if they were not supported by family, professionals and services. The multiple losses that they experienced when they lost their baby included their loss of motherhood, loss of dignity, loss of control and loss of “*normality*”. For some of the women their grief had the power to transform or the power to stifle. Judith Butler’s (2004) idea of ‘*coming undone*’ by grief allows for the exploration of the possibility that not only does infant mortality disrupt and break the woman’s world, but also disrupts and unravels her sense of self. Women in this study spoke about how infant death shattered their hopes and expectations of “*normality*” and “*normal*” birth. Women also spoke about their powerless position in Maternity services, the uncertainty and the feelings of difference due to atypical pregnancies that caused them to rethink birth, motherhood and Maternity services. In addition women’s reactions to the loss of their babies push us to re-examine the analytical framework with which to explain the conditions and reactions of bereaved mothers to grief and trauma. Some models of grief speak of ‘*symptoms*’ such as denial (Kübler-Ross, Kessler, & Shriver, 2014) which can be seen as pejorative, but the women in this study experienced denial in a multitude of ways as part of the process of managing their loss, such as “*Robocop mode*”, “*a broken record*”, “*zombie mode*” and “*blocking it*”.

Women in this study described a process of reconstructing their self and their life-world following infant death and that it was neither linear nor straightforward. These women had to reconfigure their lives as well as their relationships in a number of different ways. However Pakistani women interviewed exhibited remarkable resilience in creating conditions in which they could live on. Women in this study spoke about how infant death changed them and made them stronger. Therefore if grief and loss can have a transformative effect then it is possible to look beyond recovery and accept that for the women in this study the experience of infant death also contributed to a making of the self (Pearce, 2011). Processes that allowed women to transform following their loss involved being supported to voice their experience, having their grief acknowledged at all different levels including family, services and society as well as being visible in services.

In addition, though the experience of grief was unique to each woman, the concept of time was significant throughout each narrative. In a recent study by Barak and Leichtentritt (2014) bereaved Israeli parents were shown to experience a change in their sense of time following a sudden violent loss. The narratives of bereaved parents revealed three separate references to time; stopping, moving forward and moving backwards. Similarly, bereaved Pakistani women in this study highlighted consistently how for them time had stopped following their loss, in terms of their grief. Some participants also highlighted how their loss was as raw today as it had been when it occurred, and that the memory was frozen in their mind. Traditional models of bereavement highlighted how experiences are linear and temporally ordered for coherence and to aid sense-making (Kubler-Ross, 1969). However this view has been challenged by a “*new wave*” of grief theories that challenge the universality of grief trajectories (Neimeyer, 1999, p. 66). Bereaved Pakistani women in this study illustrated that their experiences of loss were neither contingent on time nor linear, in fact they highlighted that alternative configurations of grief exist and that loss is far more complex than what some models may propose. More recently within the literature on bereavement and grief the concept of ‘*continuing bonds*’ (Klass et al., 2014) has emerged, which seems applicable to Pakistani women in this study. Women described the positive impact on their grief when they were supported by professionals to maintain a bond with their baby through sharing their experiences with others. In contrast when women felt dismissed, neglected or ignored the capacity to process grief was diminished.

Women also described the impact of power and powerlessness on their bereavement experience. Their interactions with the professional world had the potential to empower them or in the majority of cases disempower them. Lathrop and VandeVusse (2011) highlighted that health professionals who affirmed the status of the mother, the value of the baby and the

significance of the loss were seen as supportive, whereas invalidating experiences caused significant distress to mothers. Similarly for Pakistani women in this study validating and empowering experiences supported their grief processing, whereas invalidating and disempowering experiences exacerbated their grief.

It has also been extensively documented in the literature that socially disadvantaged women encounter many economic, systemic and structural barriers when trying to access medical and maternity care (Ostrach & Cheyney, 2014). Other authors have highlighted how the structure of health care systems creates barriers which weaken the delivery of effective healthcare, particularly in relation to prenatal care (Lazarus, 1990). One of these barriers is the asymmetrical doctor-patient relationship which is magnified by social class differences (Lazarus, 1990). Women in this study demonstrated how their racial position was magnified in the health care system, particularly in relation to how much power they felt they had and how much power they were given. National policies relating to health inequalities emphasise the need for better communication between professionals and service users (DoH, 2002), particularly as they have less power in lay-professional relationships (Mir, 2008). Pakistani women took up a number of strategies to support them in overcoming these barriers such as protesting, using their ‘voice’ and becoming self-sufficient. Taking a “*stand*” and fighting for a voice as the mother of their baby was a key part of the women’s narratives.

In addition, stories of conflict with hospital services, medical mismanagement and negative outcomes of procedures are known to circulate among immigrant populations (Manderson & Allotey, 2003). In this study women described experiences of being treated as “*beds and statistics*” and “*statistical figures*” (Menzies, 1960; Obholzer & Roberts, 2003). Isabel Menzies (1960) documents some of the strategies used within hospital systems to manage professional anxiety, particularly when working with ill patients. She described strategies such as depersonalisation, categorisation and the denial of the individual through the use of “*bed numbers*” (Menzies, 1960, p. 102) as one way in which systems inhibit any form of connection with the patient. These defences and denial of the individual are some of the strategies that were highlighted by the Francis Report to have led to serious failings at the Mid Staffordshire Hospitals (Francis, 2013). Lack of awareness of these defences and an organisational culture which tolerates poor standards of care results in serious systemic failures (Francis, 2013). In relation to this study, Pakistani women powerfully illustrated the impact of such strategies on the health and wellbeing of a grieving mother, as well as on the care that they received.

Racism is a reoccurring issue in maternity services (Bowler, 1993; RCM, 2000) and often an uncomfortable subject (Cross-Sudworth, 2007). Pakistani women in this study described encountering racism in the professional world, whether this involved assumptions about the care

they deserved or clearly insensitive or derogatory comments. It has been well documented that BME women often encounter racism in maternity services (Bowler, 1993; Henderson, Gao, & Redshaw, 2013; Katbamna, 2000), however the impact of these experiences on bereaved Pakistani women's grief and narratives of loss has been less well documented. In this study negative attitudes and insensitive comments from professionals exacerbated women's grief. It often left women feeling unsafe and vulnerable in a system on which they were also dependent. Rosenblatt and Wallace (2005) have highlighted how African-Americans' experiences of racism are incorporated into their narratives of loss; they therefore suggested that a view on grief that is insensitive to the experience of racism may lead to unhelpful grief counselling. Similarly for Pakistani women an acknowledgement of the impact of racism on their bereavement experience was very important. More recently Silverman (2004) has introduced a gendered analysis of bereavement. This study suggests that for Pakistani women we need to go beyond just a gendered analysis and look at the intersections of race and religion in Pakistani women's bereavement experience.

Another master narrative was in relation to transformation and factors that helped or hindered this process of healing and change. Women described the importance of their family, particularly their husband in supporting them through their loss. It has been consistently documented that social support following infant loss is connected to the ability to process grief and long term psychological adaptation (Rajan & Oakley, 1993; Thuen, 1997). However different sources provide different kinds of support and Thuen (1997) found that professional support was particularly associated with psychological adaptation. Pakistani women in this study highlighted the importance of social support from family, spouses and professionals in helping them heal from their loss. However they were more likely to experience '*social isolation*' (Rajan, 1994) rather than support in relation to the professional world. It was these experiences that helped them recognise the need to bring about change for Pakistani women more generally. Martin Baró (1994) emphasizes how the pressure of oppressive circumstances and social structures give rise to the conditions of action. Pakistani women in the sample highlighted the transformative potential of participatory community groups for bereaved minority women as it would provide them with a safe space to process their grief and share their experiences (Small, Mir, & Fermor, 2015). They spoke about the transformative potential of '*sister-to-sister*' talk, which was similar to Silverman's (2004) gendered analysis of the conversations widows had with widows. The empowering role of participatory action groups has been well documented in the literature (Chiu, 2003), but more recently there has been a growing body of evidence in relation to the role of participatory women's groups in improving maternal and child outcomes too (Grépin & Klugman, 2011; Prost et al., 2013).

Making sense of their experience following the loss

The master narrative of sense-making included subthemes which were stories of blame, noticing inconsistencies and religion, which provided insight into the dominant influences on women's sense-making.

Women identified a number of stories of blame such as medical, cultural and self-critical. The most dominant story of blame was in relation to '*genetics*'. Pakistani women's narratives suggested that powerful discourses around "*geneticization*" (Shaw & Raz, 2015, p. 3) and cousin marriages can dominate their sense-making in relation to the loss of their baby. Medical discourses around defective genes and genetic risk contribute to locating responsibility for poor birth outcomes within Pakistani mothers and their choice of partner. However these discourses bring a strong sense of guilt and personal responsibility that women experience as distressing. Shaw and Raz (2015) highlight the increasing prioritisation of genetic over other understandings of human behaviour in Western society; Pakistani women therefore illustrated the impact of this prioritisation on their sense-making following their loss. It has also been suggested that the discourse of genetics is a modern form of mother-blaming as well as culture-blaming (Darr, 2009). Mother-blaming is neither new nor specific to a particular culture; there are many historic examples of ways in which mothers are constructed to be the sole cause of a disabled child (Landsman, 2009). It has also been well documented how in cases of infant death professionals construct particular types of maternal subjects and how these narratives about infant death reflect particular social and political discourses about bad mothers and good babies (Fordyce, 2013). However Pakistani women in this study illustrated how they experience '*double jeopardy*' (King, 1988, p. 42) through mother and culture blaming, due to their position as mothers and Asian women. King (1988) highlights the pervasive nature of dual discrimination that black women experience due to their gender and their race.

Pakistani women in this study demonstrated that the death of an infant gives rise to competing explanations of cause, professional and lay, however not all stories are equal. The story that dominates is the medical narrative (Frank, 2013). Both medical and cultural stories of blame serve to distance the experience of the birth of a disabled child from '*normal*' people, in the case of Pakistani women such an outcome happens because you married your cousin and therefore it was "*genetic*". For women in this study these discourses led to a strong sense of guilt and personal responsibility which exacerbated their grief.

Inconsistency in care, communication, advice and information often left women feeling uncertain. Women engaged in questioning and making visible inconsistencies in their experience as a way to further their understanding of their loss(es). The Institute of Medicine

(IOM) has highlighted the impact inconsistent care and communication may have on grieving parents:

“[T]hese professionals can at best help all involved feel that they did everything to help, and that preventable suffering was indeed prevented. Other times, however, families’ encounters with the health care system will leave them with painful memories of their child’s unnecessary suffering, bitter recollections of careless and wounding words, and lifelong regrets about their own choices. In between these poles of medicine, families will often experience excellent care and incompetence, attentiveness and neglect, and inconsistent communication of essential information.” (IOM, 2003, p. 104)

Faith and religion provided women with a counter-narrative to resist the dominant discourses around genetic causes of infant mortality. It also provided a counter-narrative that was encouraging and empowering rather than crushing. Counter-narratives become powerful strategies for re-shaping social reality by challenging the dominant and normative narratives. Women attempted to reclaim their experiences through preferred narratives as a way to resist the dominant discourses of infant mortality. In addition, religion allowed Pakistani women to resist the stories of blame that located the control, responsibility and outcome of birth within them. Furthermore religion also provided comfort, relief and solace to all the women during their loss. Arshad, Horsfall and Yasin (2004) state that during difficult times in their lives, many Muslims will strive to take comfort and solace through their religious beliefs. The narratives of the women suggested that religion provided them with meaning for their loss that was encouraging and empowering. As a result religion provided women with an explanation for their loss and grief that was not stigmatising nor pathologising. Women’s narratives also suggested that at times of difficulty Pakistani women maintained or rekindled their connection with Allah as a way to cope with their loss. Alahnah and Maryum spoke about receiving “*signs*” at meaningful moments in their bereavement. Spiritual experiences of presence or signs following loss of a child has been well documented, as well as its positive impact on grief (Ganzevoort & Falkenburg, 2012).

How can services develop to meet their needs?

Bereaved Pakistani women suggested a number of ways in which services could better meet their needs. When narrating the loss of their babies, intense grief was often juxtaposed with disappointment at the lack of support they had received from professionals. Therefore their narratives were replete with examples of how services could better meet their needs.

All the women in this study identified bereavement support which consisted of emotional and psychological support as well as chaplaincy as something that they would have benefited from. The finding that none of the bereaved Pakistani women were offered any form of bereavement or psychological support is consistent with literature that suggests that BME service users are regularly denied access to psychological therapy (Bhui & Bhugra, 2002; Fernando, 2002, 2003). A number of reasons have been put forward for the frequent rejection of BME service users as potential candidates for psychological support. Campling (1989) suggested that clinicians feel that their lack of cultural sensitivity may cause more harm than good, whereas Bhui and Morgan (2007) highlighted that significant cultural variations exist in the way distress is communicated as a result lack of cultural awareness among professionals can result in BME service users being missed. In addition, an ethnographic study by Norwood (2006) found that the experience of religion and chaplaincy within hospital medicine was largely one of marginalisation. Norwood (2006) revealed that religion and chaplaincy encountered both structural marginalisation resulting from inequalities in power and hierarchy as well as ideological marginalisation resulting from inequalities in accepted forms of knowledge and practice. Pakistani women in this study highlighted the impact of such marginalisation on their bereavement experience, particularly in relation to their grief processing and ability to talk about their loss. Furthermore Sheikh and Gatrad (2008) have suggested that Islam offers a reason for living and to not be offered religious/chaplaincy support may have a detrimental effect on the process of grieving.

Pakistani women in this study highlighted a number of targeted interventions that would have been helpful to them. Specialist language support and targeted care such as antenatal classes for women with a history of infant loss are some examples of practical support that could be beneficial for women. There is a longstanding and growing evidence base for targeted interventions to improve maternal and birth outcomes, particularly specialist language support (Norr et al., 2003), patient/provider racial/ethnic concordance (D'Souza & Garcia, 2004), increasing social support (Logsdon, 2000), individually tailored education (Briley, Flanagan, & Lewis, 2002) and interactive groups (Williams, Zolotor, & Kaufmann, 2009).

Being provided with opportunities to voice their experience and to witness visible change in services following the sharing of their experience can be helpful for women to process their grief and to begin to heal. BME women occupy a position at the intersection between race and gender and therefore their experiences are often invisible in mainstream policies and services (Chantler, 2002; Siddiqui & Patel, 2010; Trivedi, 2010). This study highlights the impact of invisibility on women's experience of grief and bereavement. Being visible and being seen in services was an acknowledgement of their presence and their grief. Mir and colleagues (2013b)

highlighted in their study that mothers at higher risk of infant death including Pakistani women were not represented on decision making bodies in maternity and child health services and neither were there mechanisms in place to gain feedback from these women. The lack of presence of Pakistani women on decision making bodies can result in significant experiences being overlooked and unacknowledged. This lack of representation of diverse views can result in services failing to cater for the needs of the most deprived communities including BME communities. This is exactly the point that was made by a recent ground-breaking study titled “*The Snowy White Peaks of the NHS*” (Kline, 2014). This found that BME groups were not represented on decision making bodies, particularly senior management positions which had an adverse impact on the provision of services for disadvantaged groups including maternity care (Kline, 2014). Apart from representation on decision making bodies, community engagement and participation are also key. Community participation has been long advocated to build links between health care providers and their service users as well as to improve service quality (Prilleltensky & Nelson, 2002). Women in this study highlighted the benefits of participatory women’s groups such as HOPE-Bradford and HOPE-Leeds. This offered an alternative to traditional group interventions like antenatal classes provided by Maternity services and suggested that participatory women’s group could be more empowering (Manderson & Mark, 1997).

Strengths & Limitations

The present study contributes to an important gap in the literature on the bereavement experiences of Pakistani women who are at higher risk of infant mortality than women in most other social groups. It provides novel insights into what the bereavement experience is like for Pakistani women, how they make sense of their experience and the influence of powerful discourses on their sense-making and grief. The tailored use of BNIM and a feminist and social critical perspective enabled the privileging of women’s voices and experiences. In addition the unique and successful use of Narrative Portraits provided greater depth and insight into the stories of infant mortality as well as contextualised the experiences.

A number of robust steps were taken throughout the research process to ensure the credibility of the findings and as quality checks. These included reflexivity, the use of multiple triangulation, a community of peers, respondent validation, providing evidence to illustrate findings and examples of coding. Therefore though there are clearly strengths to this study, there are also some limitations that need to be considered.

Sampling, sample size and generalizability

First, all seven women who participated in the study had previously been involved in the Social Networks and Infant Mortality Study, therefore this may have influenced the stage they were at in terms of processing their experiences. All seven women had experience of speaking publicly about their bereavements and therefore this may have influenced how comfortable and forthcoming they were in the interview, as well as whether their narrative was streamlined or rehearsed. Nonetheless, it is likely that women who are open to sharing their experiences, views and opinions can provide richer and more comprehensive data.

A further limitation could be the characteristics of the sample, for example six of the women had predominantly negative experiences of Maternity Services. However despite this within each woman's narrative there were examples of both positive and negative relationships with professionals and systems. Therefore though the women may have had overwhelmingly negative experiences, they openly discussed times when they had experienced positive healthcare which allowed the identification of good practice and areas for service development.

Six of the seven women in the sample were fluent in English and another limitation could be about whether their narratives reflect the experience of Pakistani women as a whole. One way to address this limitation would be to interview non-English speaking Pakistani women. Despite this evidence from the literature suggests that non-English speaking BME women do report similar experiences to the ones described by Pakistani women in this study, therefore there is likely to be commonalities in their experience (Bowes & Domokos, 2003; Bulman & McCourt, 2002).

In addition women's experience of infant loss ranged between 2 to 18 years ago which has many strengths and limitations. One argument could be about whether women's experiences are applicable today and that whether services have changed. However capturing a group of women's experiences across a large timeframe helps identify reoccurring patterns. For example all seven women were not offered any bereavement support regardless of when they lost their baby. In addition evidence from the Francis Report (Francis, 2013), the Cumbria Police Investigations and the RCM (RCM, 2012) suggests that the level of support offered in services has actually become worse, not better.

In regards to generalisation, although narrative approaches explore and interrogate individual cases it does not mean that the results cannot be generalised. Quantitative and statistical approaches generalise from a sample to the entire population. Narrative studies on the other hand can involve "*generalisation to theoretical propositions*" (Bryman, 2003, p. 78), which are to some degree transferable. Riessman (2008) has also pointed out that making

conceptual inferences about a social process is an equally “*valid*” form of inquiry, with a long history in anthropology and sociology (Riessman, 2008, p. 13).

Biographic Narrative Interview Method

There were a number of strengths and drawbacks to using BNIM in this study. In general it appears that it is an appropriate method to be used with bereaved Pakistani women as it is empowering and provides a space for the women to construct their own narrative. However it is also important to bear in mind that some women may struggle with this method and therefore may need support and encouragement to use opportunities offered to them. Empowerment is seen as something that can be done to others and as researchers we are told we should empower participants to take control of their life stories (Perkins & Zimmerman, 1995). However in this study one woman struggled with the method, highlighting that empowerment is different for all women and is dependent on the position of the woman in society, including their race, religion, education and social class. In addition “*even the most articulate among us face difficulties when we try to put ambiguous and jumbled thoughts and images into words. This is even truer of someone who has suffered traumatic loss*” (Das, 1990, p. 49). Therefore when BNIM is used flexibly i.e. providing gentle guidance and encouragement when appropriate then it can be successfully used with bereaved Pakistani women.

Clinical Implications

The research findings and the narratives of the women suggest a number of clinical implications and areas for service development. One of the key implications was the potential usefulness of representation of Pakistani women on decision making bodies in Maternity, Child Health, Paediatric Psychology and the new Infant Mental Health services. There are clearly opportunities to increase the involvement of Pakistani women in the design, development and running of these services.

In addition, women’s grief narratives suggested a number of ways in which services could ease the bereavement experience particularly in relation to supporting women in continuing their bonds with their baby. The provision of bereavement support which includes psychological support and chaplaincy is also very important in order to meet the needs of bereaved Pakistani women.

The study also highlighted the need for targeted interventions and support such as specialist interpreting services, individual, family or couple based interventions for bereaved women as well as group based interventions. In line with the growing literature, Pakistani women demonstrated the invaluable role of participatory women’s groups. Therefore there is a clear need for services to explore the potential of facilitating the development of participatory

women's groups as a method for allowing women to contribute to decision-making. The study also highlighted that bereaved Pakistani women valued a narrative approach to interviewing and therefore narrative therapy for grief may also be a useful intervention. There is evidence to suggest that Grief Counselling and Narrative Therapy can be combined and that it is beneficial in relation to bereavement support (Neimeyer et al., 2010; Neimeyer & Currier, 2009).

Training for staff to tackle racism and to build their confidence in working with BME women may also be highly valuable (Cross-Sudworth, 2007). In addition the recruitment of BME staff may be helpful in representing the diverse views and needs of disadvantaged communities (Cross-Sudworth, 2007; Mir et al., 2013a).

Future Research

Though the current study introduced novel insights into the bereavement experience of Pakistani women following infant mortality, it also highlighted future research that could be beneficial. Pakistani women highlighted the importance of maintaining bonds with their babies therefore it is important to explore how professionals and services could support Pakistani women to maintain such bonds. In addition future research could also explore the impact of targeted interventions such as narrative therapy and participatory women's groups on the bereavement experience of Pakistani women.

In addition Pakistani women consistently demonstrated the important role of professionals in their grief processing. Therefore future research could explore of staff views and perspectives on maternity wards when BME women lose a baby, particularly around staff needs and what training and support could be put in place to support them in their roles.

CONCLUSIONS

This study explored the bereavement experiences of Pakistani women following infant mortality. The research specifically explored Pakistani women's bereavement narratives in two multicultural sites in the UK. It provides novel insights into what the bereavement experience is like for Pakistani women, how they make sense of their experience and the influence of powerful discourses on their sense-making and grief. The findings demonstrated that Pakistani women's bereavement experiences were similar and different to dominant understandings of grief processes. The findings were also consistent with existing literature on women's experience of infant mortality and the psychological impact of loss. However the study offered further insights into how the process of bereavement may be different and unique for Pakistani women, such as how grief, power, uncertainty and the possibility of transformation were interconnected and influenced by the system in which the women found themselves. Women also highlighted the powerful stories of blame, predominantly medical, which located responsibility for infant mortality and poor birth outcomes with parents. These stories of blame had powerful and devastating implications for Pakistani mothers who often as a result blamed themselves. Pakistani women also highlighted a number of ways in which services could develop to better meet their needs such as targeted interventions, being visible in services and being heard. There is a role for Chaplaincy within Maternity Services, particularly as all seven women reported not receiving any spiritual or religious intervention, despite this being significant in their grief process. The results also suggest that there is a role for practitioners to provide emotional and psychological support, particularly to BME mothers and families when babies are admitted on Neonatal Intensive Care Units and when babies die. Clinical Psychology could have a role to play in supporting, supervising and training staff, particularly nurses, midwives and health care support workers to provide the necessary conditions for BME mothers to grieve and feel safe in Maternity services.

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ABBREVIATIONS

BDIMC:	Bradford District Infant Mortality Commission
BME:	Black & Minority Ethnic
BNIM:	Biographic Narrative Interview Method
BPS:	British Psychological Society
DoH:	Department of Health
ESRC:	Economic & Social Research Council
FSID:	Foundation for the Study of Infant Deaths
IMNST:	Infant Mortality National Support Team
IPA:	Interpretative Phenomenological Analysis
MSLC:	Maternity Services Liaison Committee
NAO:	National Audit Office
ONS:	Office for National Statistics
PARF:	Population Attributable Risk Fraction
RCM:	Royal College of Midwives
SIDS:	Sudden Infant Death Syndrome
SQUIN:	Single QUestion aimed at Inducing Narrative
TQUIN:	Topic QUestion aimed at Inducing Narrative
WHO:	World Health Organisation

APPENDIX

Appendix I – Search Strategy

All relevant studies regardless of language or publication status were identified and reviewed. In terms of electronically searching databases, the following databases were searched:

- The Cochrane Library
- PsycINFO
- MEDLINE
- EMBASE
- Web of Science
- Ovid
- PubMed Central
- CINAHL
- Global Health
- ScienceDirect
- PakMediNet
- Pakistan Psychological Abstracts
- National Institute of Psychology

The following search strategy was used, in combination with text word terms and controlled vocabulary, it was also modified accordingly for each database searched. The main filter terms were:

1. Infant Mortality
2. Perinatal
3. Neonatal
4. Infant death
5. or/ 1-4
6. Maternity services
7. Satisfaction
8. Experiences
9. Or/6-8
10. 5 & 9
11. Bereavment
12. Loss
13. Grief
14. Or/11-13
15. 5 & 14
16. Black and Asian
17. BME
18. Ethnicity
19. Pakistani
20. African
21. Race
22. Or/16-21
23. 22 & 5
24. 22 & 9
25. 22 & 14
26. 22 & 5 & 14

Appendix II – Biographic Narrative Interview Schedule

Introduce self; go through information sheet/answer questions; anticipated timescale (up to 90 minutes); option to have a break at any time or terminate the interview. Consent.

Check support available should participant become distressed during the course of the interview.

Core Question:

“As you know I am doing research into the bereavement experience of women who have lost a child. Can you please tell me about your experience of bereavement and any support you received? You can tell your story in any way you feel comfortable, all the events and experiences that were important to you...perhaps beginning with telling me a bit about when problems first started to occur, what happened immediately afterwards and your journey since the death...”

I will listen first and not interrupt you while you are telling me what happened to you, but I will take some notes so I can ask you questions about it when you have finished,”

After the participant has finished speaking:

“I will just take a few minutes to read through my notes if thats ok, before asking you some more about what you have told me.”

Prompts & Follow-up Questions (specific incidents):

“You said XXXX could you tell me a little more about how that happened?”

“You said XXXX, I wonder if you can remember any particular incident or occasion when XXXX?”

“Can you give me any more examples of similar events, incidents at that time/of that type?”

“Was there some particularly important incident or situation or time that you can remember?”

“Could you tell me what happened before/during/after?”

“Then what happened?”

“Could you tell me where this was?”

“Do you remember who was involved?”

“Could you tell me more about that?”

Check how participant is feeling. Provide contacts for bereavement support organisations

Appendix III – Demographic Details

Name	
Age	
Country of Birth	
Health Status	
Employment Status	
Educational Level	
Religion	
Family	
Baby's name	
Cause of death	

Appendix IV – BNIM Pin Sheet

BNIM SHEIOT notepad

(Situation, Happening, Event, Incident, Occasion/Occurrence, Time)

SQUIN:

“As you know I am doing research into the bereavement experience of women who have lost a child. Can you please tell me about your experience of bereavement and any support you received? You can tell your story in any way you feel comfortable, all the events and experiences that were important to you...perhaps beginning with telling me a bit about when problems first started to occur, what happened immediately afterwards and your journey since the death...I will listen first and not interrupt you while you are telling me what happened to you, but I will take some notes so I can ask you questions about it when you have finished.”

Allow responses with continuous active listening. Some of initial question can be repeated if a prompt is required, but no further prompting in this section. Work hard to keep open space for free response.

	—————→		ILLUMINATION ONLY by MORE STORY
Themes in the order mentioned and in the terms used by the interviewee	Relatively <i>General</i> terms about <i>Situation, Time, Phase</i>	More <i>Particular</i> terms about <i>Incident, Happening, Occasion, Event</i> “How it all came about” “How all of that happened”	e.g. <i>You said</i> <i>“XXXX”- can you tell me more about how all that happened?</i> <i>Or- do you remember any particular incident or occasion when XXXX?</i>
<i>Their keywords</i> for your eventual return-to-narrative questions			<i>Full versions</i> of your eventual return-to-narrative questions

Appendix V – Infant Mortality & Social Networks Study Inclusion Criteria



Infant Mortality and Social Networks Study: Recruitment Protocol and Information for Recruitment Partners

What is this study about?

The link between infant mortality and social exclusion is well documented, and women in some minority ethnic communities as well as teenage mothers are known to be at particular risk of experiencing the death of a baby before the age of one. Although health care policies highlight the increased risk for these women and the need for improved services, there is little research evidence about how professionals can effectively meet their needs. In addition, there is a need to involve service users in shaping health services that can effectively meet their needs.

This study investigates the support available to women in relation to maternal and infant health in a range of ethnic and social groups. A new approach using social network analysis and participatory research will be used to explore the extent and nature of women's personal and formal support networks and solutions to address inequalities in birth outcomes.

Further details of the study are available here:

<http://www.leeds.ac.uk/hsp/hr/research/AUPBS/infant-mortality.html>

Who are we recruiting?

We have ethical approval to interview women in Leeds and Bradford, some of whom have experienced an infant death, as well as those who have a healthy child over the age of one. **At this stage we would like to interview women from Pakistani and African or Caribbean communities, as well as teenage mothers, who have experienced an infant death.** We recognize the sensitivities of recruiting women who have lost a child, however it is important for them to have the opportunity to contribute to service development in this area. Participating in this study offers women a safe place to tell their stories; women who have already been involved in the study have appreciated the chance to contribute. There will be an opportunity for women to be involved in designing and implementing new interventions to address the barriers to support that we identify.

What do recruitment partners need to do?

Recruitment will be in two stages:

1. We would like to interview women from Pakistani and African or Caribbean communities and teenage mothers who have experienced an infant death. Women already known to recruitment partners who they feel may be suitable should be invited to participate. Looking at healthcare



records may be helpful to trigger recall of women in these groups. The appropriate time at which to ask bereaved mothers if they wish to participate will be determined on a case by case basis and the decision will be led by the recruitment partner. However, general advice from the Foundation for the Study of Infant Deaths (FSID) suggests that interviewing women at least 6 – 12 months after the loss of their child may be most appropriate.

The recruitment partner should ask mothers if they have been provided with details of the study. If mothers have already been provided with details the recruitment partner will not pursue this further.

Recruitment partners will provide potential participants with the **information sheet**, which gives more details about how the women would be involved. **There is also an additional details sheet that should be completed by the referrer and sent to the researchers.**

2. Women will be contacted by the researchers by an initial phone call and a letter with the researchers' contact details. This will enable them to discuss any further questions with the researchers before making a final decision to participate. Formal consent will be obtained at this point and the women will have the option to opt out at any time.

What will participants need to do?

Participants will meet one of the researchers on a one to one basis for an interview of about 60-90 minutes. During the interview, the researcher will ask questions about the support women received during pregnancy and delivery as well as in the following weeks. In recognition of the sensitive subject area there is a protocol for dealing with distress during the interview process. Written information about local organisations for support and counselling will be provided to every participant. There will be a small payment or gift for each participant in recognition of the time they have given to be involved in the study.

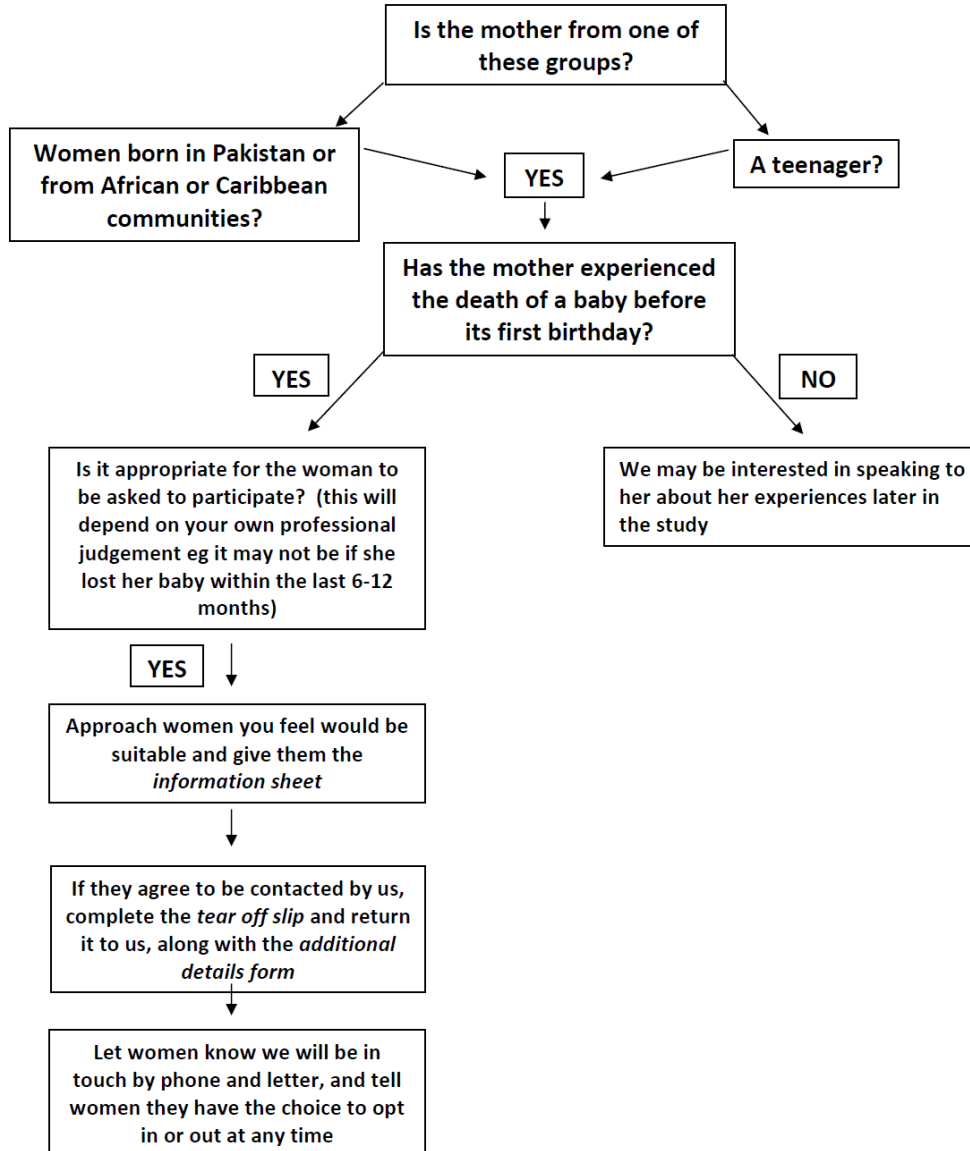
For more details or to discuss this information sheet or the accompanying flowchart, please contact Katie Spicer or Ghazala Mir:

Katie Spicer, Research Fellow at Leeds Institute of Health Sciences, University of Leeds, 101 Clarendon Road, Leeds LS2 9LJ. Tel: 0113 343 0835; email: k.spicer@leeds.ac.uk

Ghazala Mir, Senior Research Fellow at Leeds Institute of Health Sciences, University of Leeds, 101 Clarendon Road, Leeds LS2 9LJ. Tel: 0113 343 4832; email: g.mir@leeds.ac.uk



Infant Mortality and Social Networks Study: Recruitment Flowchart



Appendix VI – Invitation Letter

UNIVERSITY OF LEEDS

Doctor of Clinical Psychology Programme

Charles Thackrah Building
University of Leeds
101 Clarendon Road
Leeds LS2 9LJ

Website: www.leeds.ac.uk/lihs



[Address]

[Date]

Dear [Name]

Understanding the bereavement experiences of Pakistani women following Infant Mortality – Invitation to take part in research

I am writing to follow up from my meeting with the HOPE Group on 14th March 2013 regarding the research study that I am conducting. Thank you for agreeing to be contacted about the study, I attach a copy of the information sheet for your information.

I am writing to ask if it would be convenient to visit you on (date and time). I will contact you by telephone in the near future to discuss the research with you further, answer any of your questions and to check if this date and time is suitable for you.

Yours sincerely

Romana Farooq
Clinical Psychologist in Training

Appendix VII – Participant Information Sheet



UNIVERSITY OF LEEDS
Doctor of Clinical Psychology Programme

Information sheet: Understanding the bereavement experiences of Pakistani women following Infant Mortality

What is the research about?

Infant Mortality rates are particularly high among Pakistani, African and Caribbean women in the UK. Yet there is limited research on what this may be like for these women and what types of support may be helpful. Therefore this study aims to explore the experiences of Pakistani women who have lost a baby.

The study also aims to identify whether bereavement support may be helpful to Pakistani women and what it might look like. It will also investigate how Psychology, Counselling and Maternity services can meet the needs of Pakistani women who have lost a baby. The information we gain through interviews will be used to look at what the experiences of infant mortality are like for Pakistani women, how they made sense of the loss and whether tailored bereavement support is needed.

Why is this research important?

The number of children who die before the age of one year is higher for some women than it is for others, for example, for women in some minority ethnic communities. Improved services and support for women who are at a higher risk are important ways of reducing the risk. However, at the current time, knowledge about how best to provide support for women from disadvantaged groups is limited. This study will increase our knowledge about where the gaps are in services and how to better meet their needs. The study will also be the first to provide an in-depth analysis of the psychological needs of Pakistani women following infant mortality.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You can withdraw from the research at any time and without giving a reason. Your decision will not affect any support that you receive.

What will happen to me if I take part?

A student researcher (Romana Farooq) from the University of Leeds will contact you and come to visit you at a time that suits you. The researcher will make sure you understand about the research and will ask you to sign a form saying you are willing to take part. The researcher will arrange a time to interview you and ask you questions about your experiences of losing a child and the support that you received. The interview will last up to 90 minutes. All the information you give will be kept within the research team only. If you agree, the interview will be recorded on a tape recorder. This is to ensure that we do not miss anything you feel is important. Recordings will be destroyed after the project is finished. If you change your mind about taking part you can stop at any time and this will not cause any problems.

How will we tell people what we find out?

The information that you provide during the interview will be analysed and written up by the Research Team. You will be given an opportunity to look at the interview transcript, analysis and report if you want to. Following this we will publish a report that will be sent to people who work in health and social care settings, people who use maternal health services and relevant community organisations. We will not use names or personal information in any way that would mean you could be identified.

Who has reviewed this study?

The South Yorkshire Research Ethics Committee has reviewed and given a favourable opinion to this study.

Who can I contact?

If you want to discuss the study further then please contact Romana Farooq at University of Leeds, Doctor of Clinical Psychology Programme, Charles Thackrah Building, 101 Clarendon Road, Leeds, LS2 9LJ, Email: umrf@leeds.ac.uk or telephone: 0113 343 0815

You can also contact the Research Supervisors Dr Ghazala Mir or Dr Fiona Thorne at University of Leeds, Charles Thackrah Building, 101 Clarendon Road, Leeds, LS2 9LJ or telephone: 0113 343 4832/2732

If you have any concerns about any aspect of this study, you should ask to speak to the Researcher who will do their best to answer your questions. However if you remain unhappy and wish to complain formally then you can do this by contacting: Clare Skinner, Faculty Head of Research Support, Faculty of Medicine & Health Research Office, Room 10.110, Level 10, Worsley Building, University of Leeds, Clarendon Road, Leeds, LS2 9NL or telephone: 0113 343 4897

Thank you for taking the time to read this information sheet

Appendix VIII – Consent Form



UNIVERSITY OF LEEDS
 Doctor of Clinical Psychology Programme

Consent Form: Understanding the bereavement experiences of Pakistani women following Infant Mortality

Please Initial
1. Have you read the information sheet?
2. Have you had an opportunity to ask questions and discuss the research?
3. Have you received satisfactory answers to all your questions?
4. Do you understand that you are free to leave the study: a. at any time b. without having to give a reason c. and without affecting any support you receive
5. Do you have someone who you can go to for support after the interview if you need it?
6. Do you understand that your details will not be passed on to anyone?
7. Do you agree to anonymised data being used for other research purposes?
8. Do you agree to take part in this study?
Signed Date Telephone number (to arrange a time to meet) Name (block capitals) Address Researcher Signature Date <p style="text-align: center;"><i>1 copy for the participant and 1 copy for the researcher</i></p>

Appendix IX – Ethical Approval Documentation



Health Research Authority

NRES Committee Yorkshire & The Humber - South Yorkshire

North East REC Centre
Unit 002, TEDCO Business Centre
Rolling Mill Road
Jarrow
Tyne and Wear
NE32 3DT

Tel: 0191 428 3566
Fax: 0191 428 3432

03 October 2013

Dr Ghazala Mir
Senior Research Fellow
University of Leeds
101 Clarendon Road
Leeds
LS2 9LJ

Dear Dr Mir

Study title: Social Networks and Infant Mortality: the impact of bonding and bridging outcomes for women from diverse backgrounds.
REC reference: 11/YH/0017
Amendment number: Substantial Amendment 1
Amendment date: 06 September 2013
IRAS project ID: 73035

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

Members of the sub-committee reviewed the application for substantial amendment and asked for the following issues to be addressed:

It was not clear from the amendment form what changes were being requested and further clarification should be provided.

You responded that the changes requested for this amendment were:

- An extension of ethical approval to 31st September 2015 to allow linked projects by three University of Leeds students to take place. Romana Farooq's project on bereavement support would be undertaken for her Doctorate in Clinical Psychology. Aafreen Rahman and Qasim Sheikh's project on potential service developments in genetic counselling would be conducted as part of their MBChB degree. Both these project areas have already been identified as priorities by research participants involved in the current study. Both projects will take place under supervision of the Chief Investigator.
- Additional focus group discussions and individual interviews. In relation to the project on bereavement support, a number of women involved in the current study have agreed to be interviewed on their experience of receiving bereavement support. In relation to the additional work on genetic

counselling, consent will be sought to hold a focus group discussion with women involved in the current study, and to conduct individual interviews with a small number of relevant professionals and the husbands of women involved in the current study, to provide further detail on appropriate models of support. This additional activity has been identified as needed by women involved in the current study and will be conducted under Phase 4 as “work to improve relationships between healthcare providers, women using maternity services and family members or to increase access to information or resources for health”.

Members requested further clarification on the Narrative Interview Schedule, especially whether this would be delivered in the participants' language or just in English.

You explained that the Narrative Interview Schedule would focus on an initial question to allow participants to tell their story about bereavement in their own way and focusing on their own priorities. Prompts detailed on the schedule will be used to elicit further relevant details if these were not covered by the initial narrative. Romana Farooq is bilingual and would be able to interview in Punjabi, the language of one of the women who has agreed to be involved in this linked study. Other participants are all English-speaking but may use Arabic and Urdu terms, with which Ms Farooq is also familiar

The committee queried whether there would be any support mechanisms in place for any participants who became distressed.

You explained that a protocol has been developed for the main study along with contact details of support organisation for any participants who become distressed. In addition, as a result of the current study, participants have developed links with a national bereavement support charity, SANDS, to develop culturally appropriate provision, which is expected to be in place by the time interviews for Ms Farooq's study begins. Participants will be asked before these interviews whether they have access to a source of support should they become distressed during the course of the interview; interviews will only take place if such support is considered by participants to be accessible if necessary. Details of the support organisations, including the newly developed groups, will be offered to every participant at the end of the interview

Members felt that on the Narrative Interview Schedule, the question “If you had to re-write your experience what would you change?” should be re-worded because participants may misunderstand this and reply that they didn't want their child to die.

You appreciated the feedback on the interview question and would re-word this to “If you could re-write your experience, are there any aspects of the bereavement support you received that you would change?” A revised interview schedule with amended version number and date was attached with highlighted changes, including clarification of the processes outlined above.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date	
Letter responding to points raised by sub-committee		30 September 2013	

Notice of Substantial Amendment (non-CTIMPs)	Substantial Amendment 1	06 September 2013	
Protocol for dealing with distress		30 September 2013	
CV for Qasim Sheikh			
Narrative Interview Schedule	2	30 September 2013	
CV for Aafreen Rahman			
CV for Fiona Thorne			
List of Support Organisations in Leeds & Bradford	2	30 September 2013	
Cv for Romana Farooq			
Covering Email		30 September 2013	
Narrative Interview Schedule			
Covering Letter	Email from Ghazala Mir	11 September 2013	

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

11/YH/0017:	Please quote this number on all correspondence
-------------	--

Yours sincerely



**pp Ms Susan Hampshaw
Chair**

E-mail: nrescommittee.london-camdenandislington@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Mrs Jane Dennison, Bradford Teaching Hospitals NHS Foundation

A Research Ethics Committee established by the Health Research Authority

Trust

Mrs Rachel E de Souza, University of Leeds

Appendix X – Protocol for Dealing with Distress

Infant Mortality and Social Networks

Protocol for dealing with distress

- The length of time that should be allowed prior to requesting participation in the study will be discussed on an individual basis with professionals involved in recruitment along with prior assessment of risk for potential distress and an agreed process for providing support if required.
- Participants considered likely to be overly distressed will be excluded from the study.
- The research interviews will be undertaken by research staff who have experience of work and/or previous research in health care settings. In addition, the researchers have had previous experience of interviewing people where the topics explored are of a sensitive nature. The researchers will be able to deal with normal levels of distress that might arise at the time of the interview.
- In the event that a participant becomes distressed during an interview, an escalating support framework for different levels of distress will identify the form and route for appropriate support.
 - Contact details for relevant support organisations, compiled in collaboration with research partners, will be available for all women.
 - Any distress a participant experiences will be discussed in a sensitive and appropriate manner at the time, and clarification sought as to whether the participant has sources of informal support such as family or friends.
 - The researcher will discuss whether the participant wants to contact a health professional such as a GP or health visitor. The researcher will discuss the participant's plan for seeking support, including the timescale, and offer to contact this person on behalf of the participant. However the researcher will usually only contact the professional if the participant gives consent for this.
 - The researcher will offer to ring the participant on the following day if s/he is felt to be particularly distressed.
 - If the participant does not consent to either a follow up phone call by the researcher or contact being made with the professional involved in recruitment, or if a safeguarding issue arises, the researcher will take advice from Dr Fiona Thorne who is providing supervision for the project.

Protocol for dealing with distress 30.9.13

- Training will be organised for researchers on bereavement research and dealing with distress to ensure they are equipped to carry out actions described in the protocol eg attendance at bereavement conferences and advice from SANDS. Researchers will take advice from those with relevant experience from within the research partnership and local collaborators during the course of the study as required.

Appendix XI – List of Support Organizations

Support Organisations in Leeds and Bradford

- **Bereavement Midwife:** Julie Key, Bradford Royal Infirmary, Duckworth Lane, Bradford BD9 6RJ. Contact via hospital switchboard: 01274 542200
- **Hospital Chaplains at BRI:** Maryam Riaz and Shaheen Kauser 01274 365819 and **Leeds:** Dr Sara Calcattawala sara.calcattawala@leedsth.nhs.uk 0113 2064160/2064365
- **SANDS:** Stillbirth and Neonatal Death Society. Provides support anyone who has been affected by the death of a baby and wants to talk to someone about their experience. Sands National Helpline: 020 7436 5881, e-mail: [helpline\(at\)uk-sands.org](mailto:helpline(at)uk-sands.org), website: <http://www.uk-sands.org/>
- **Leeds SANDS group:** <http://www.leeds-sands.org.uk/> and 07518 917594
- **Bradford SANDS group:** daytime support offered for South Asian parents as well as an evening session for parents from diverse backgrounds. Contact: Josie Watson josiewat@fsmail.net
- **BLISS:** ‘for babies born too small, too sick, too soon’. Provides support for parents of babies in Special or Intensive Care Units and for bereaved parents. Family Support helpline, freephone, 0500 618 140. Website: <http://www.bliss.org.uk>
- **Child Death Helpline:** helpline for anyone affected by the death of a child of any age, from pre-birth to adult, under any circumstances, however recently or long ago. 0800 282 986.
- **The Child Bereavement Charity:** supports families and educates professionals both when a child dies and when a child is bereaved. Support and information line: 0494 568900. Website: <http://www.childbereavement.org.uk/>
- **Childhood Bereavement Network:** works with bereaved children and young people. They believe that young people should be provided with information, guidance and support to help manage the impact of death on their lives. Tel: 020 7843 6309, Email: cbn@ncb.org.uk. Website: <http://www.childhoodbereavementnetwork.org.uk>
- **Foundation for the Study of Infant Deaths (FSID):** provides a helpline which is open to bereaved parents and their families, friends, neighbours and anyone else who has experienced the sudden death of a

baby, pregnant women, new mums and dads looking for safe baby care advice and anyone else who has questions about the sudden death of a baby or how best to reduce the risk of cot death. Helpline: free-phone 0808 802 6868, e-mail: helpline@fsid.org.uk. Website <http://fsid.org.uk>

- **Bradford Bereavement Support:** www.bradfordbereavement.org.uk Tel: 01274 619522
- **Off The Record: Bradford Counselling Services:** free counselling for young people aged 13-18, and sliding scale fees for adults. Covers bereavement and other issues. www.offtherecord.org.uk Tel: 01274 733080
- **Womens Health Matters (Leeds):** an independent voluntary organisation run by women for women. They aim to work with women so that together they can take control of their lives and their health. Tel: 0113 276 2851. Texts only: 0750 423 2989. Email: admin@womenshealthmatters.org.uk. Website: <http://www.womenshealthmatters.org.uk>
- **Women's Counselling and Therapy Service Leeds:** supports the mental health and emotional well being of women living in Leeds, prioritising those on a limited income. Tel: 0113 245 5725, website: <http://www.womenstherapyleeds.org.uk/>
- **Antenatal Results and Choices:** national charity which provides non-directive support and information to expectant and bereaved parents throughout and after the antenatal screening and testing process. Tel: 0207 631 0285 <http://www.arc-uk.org/>

Appendix XII – Validation Letter**UNIVERSITY OF LEEDS**

Doctor of Clinical Psychology Programme

Charles Thackrah Building
University of Leeds
101 Clarendon Road
Leeds LS2 9LJWebsite: www.leeds.ac.uk/lihs

[Address]

[Date]

Dear [Name]

Understanding the bereavement experiences of Pakistani women following Infant Mortality – Your Narrative Portrait

I am writing to follow up from my phone call earlier in the week. As discussed I am currently writing up the findings from our Interview last year. I have therefore created a Narrative Portrait of the interview context, our relationship from my perspective and a short summary of your bereavement experience. The Narrative Portrait is attached for you to read and comment on. I have also attached a Thematic Map which illustrates some of the key themes that emerged from all the interviews I conducted with the women.

It would be good to hear your views on both of these and whether they capture your experience. I would also be happy to hear your views on whether you would like to delete, change, correct, add or develop anything. I am available on [date and time] to either talk on the phone or visit you at home, so please let me know what suits you

Yours sincerely

Romana Farooq
Clinical Psychologist in Training

Appendix XIII – Thematic Framework

Research aims and questions:

1. What are the experiences of Pakistani women in the UK in relation to infant mortality?
2. How do these women make sense of their experience following the loss [of an infant]?
3. Do the narratives of these women suggest ways in which services might develop to meet their needs?

1) Experience of Infant Mortality

1a) Context/Setting the scene		
1b) Warning Signs		
1c) Ethnicity		
1d) Investigations		
1e) Diagnosis	Labels	
1f) Breaking the News		
1g) Normality	Stigma	
1i) Leaving Hospital/coming out		
1j) Costs/Implications		
1k) Being a mother		
1l) Final Moments		
1m) Funeral		
1n) Living on		
1o) Subsequent Pregnancies		
1p) Emotional Impact	Fear/Scared Emptiness Alone/Isolated Uncertainty Grief	Time Re-membering Being acknowledged Blocking it out Attachment Depression
	Mental Health	

	Hope Bereavement Support		
1q) Relationships	Professional world & Interactions	Positive Negative Attitudes Language support Voice Power Access	Counselling Chaplaincy Emotional support Information
	Family	Husband Children Bereaved women	Bond
	Women Trust Systems/services		
		2) Making Sense	
2a) Stories of Blame:	Genetics Cultural/societal Self-critic		
2b) Religion			
2c) Inconsistencies			
		3) Other	
3a) Research Method			
3b) Service Improvement	Targeted support		

Appendix XIV – Example Chart

Participant	Emotional Impact			
	Feeling Scared	Uncertainty	Grief	
			Time	Blocking it out
Zaara	<i>"I think throughout all my pregnancies I've been really scared...there's been...[10 second pause] more.....I think when you fall pregnant again you are, you've got the last experience shadowing....the current experience and you're always scared. I'm still scared and I've had a successful, Alhamdulillah..."</i>	<i>"But I was very early, so I didn't have any comprehension as to...because it was so far ahead, I hadn't prepared myself for labour and I didn't know what the symptoms were for labour or premature labour...because my ante natal classes hadn't started till the following week. I think I would have been entitled to start them at that week."</i>	<i>"You never get over your experiences, you never get over that grief. And that experience will always taint your experience and it always taints my experience to the extent that I'm always telling other people my experience to make sure that they know what to look for..."</i>	<i>"It just felt like I was...how could this be happening to me. This is not a miscarriage because I've had my miscarriages. They said it's normal before 12 weeks. This is not normal. Nobody's warned me about this...so, this is not happening to me. This is happening to somebody else. It is happening to her.' It's like a metamorphosis experience."</i>
Sonia	<i>"I was too scared to go downstairs, you know, because you have to go...because everything's...you know, it's so bizarre, something's happened. Why should it happen? You are supposed to have your baby. Be happy and, hopefully, take baby home. Unfortunately, no."</i>	<i>"So, we had this conscious in our heads, thinking 'oh, God, any day.' You know, every day was like 'oh, my God. Is it today? Is it today?'"</i>	<i>"I don't think I will ever get over my son. Ever. He was just the best baby ever."</i>	<i>"And, obviously, the doctors said 'it is a condition where babies do not survive.' Obviously, we didn't want to hear that. I used to think 'right, okay.' Some days I would say 'I'm not listening to the doctors. Let them say what they want because they're telling me a story from a book because, obviously, they've been educated that way."</i>
Alahnah	<i>"When I went, she was so helpless. She was so small I was scared to touch her. And I remember this nurse comes up to me and she goes 'do you wanna hold her?' And I thought [sighs] 'no, I just want to leave her there'. I go 'she's in peace' and then I came, we came upstairs."</i>	<i>"Because her immune was really weak it took time, it were taking time for her to, the chest infection, the pneumonia to clear. And I was like 'well why isn't she getting better? It's been like a week now and you know I want to take her home'. And then they said 'oh it's because she's poorly and she's got other things going on and its taking time for her to'"</i>	<i>"He never missed an appointment [sighs] he never missed any of her appointments [crying] he used to go with her inside to doctors to see what the doctors were saying about her [crying] She would have been 16! [sighs] its erm, you know they say time heals it, it doesn't [crying]"</i>	<i>"I remember coming home and my sister came, my husbands friend came and I just went into the kitchen and I started mopping up and cleaning up and then my husband comes into the kitchen saying to me 'do you know what has happened?' and I'm like 'do you want tea?' I remember asking him if he wanted tea."</i>