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Beyond Bereavement: is close kinship enough?

An exploration of the bereavement experiences and support in Gypsy and Traveller families

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Beyond Bereavement: is close kinship enough?

An exploration of the bereavement experiences and support in Gypsy and Traveller families

By
Carol Rogers
Doctorate of Philosophy
August 2016

Coventry University
Buckinghamshire New University

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A thesis submitted in partial fulfilment of the University's requirements for the Degree of Doctor of Philosophy

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Abstract

The purpose of this research is to gain an understanding of the cultural norms and community practices influencing the bereavement experiences of Romani Gypsy and Irish Traveller families in England. The aims and objectives set out to explore the impact of bereavement on individuals and wider family members. To identify whether bereavement has a long term impact on their life experiences, and to explore the extent to which membership of a close-knit family and community, with explicit cultural norms offers effective support for managing the processes of loss, or potentially exacerbates the risk of long-term complicated grief.

The research was undertaken in partnership with the Child Bereavement UK and a number of Gypsy and Traveller support organisations. The study has a phenomenological paradigm and uses a narrative approach, focus groups and narrative conversations to gain an understanding of the bereavement experiences of Gypsy and Traveller women. Consideration is also given to potential bereavement support needs and how best organisations can tailor their policy and practice to meet the needs of these 'hard to reach' populations.

Gypsies and Travellers remain one of the most marginalised ethnic minority groups in Britain. Policy enactments and a decline in stopping places have impacted on their cultural tradition of nomadism, leading to significant socioeconomic challenges and rapid cultural change in recent decades. Additionally, Gypsies and Travellers face significant health inequalities, including a reduced life expectancy of between ten to twelve years compared to 'mainstream' populations. Furthermore considerably higher levels of suicide, maternal and infant mortality, miscarriage and stillbirth are reported. The numerous intergenerational bereavements experienced can result in complicated and prolonged grief reactions with long term health implications including depression, anxiety and an increase in risk taking behaviours including alcohol and substance misuse.

The research findings suggest that the close knit nature of Gypsy and Traveller communities means that the death of a relative is felt with great intensity, articulated by some research participants as an event that they '*never come to terms with'*. Consequently complex family relationships and stoic attitudes result in personal grief responses often becoming hidden losses as highly protective behaviours place the needs of others above that of the individual; thus family becomes a barrier rather than support mechanism following bereavement.

The research offers new insights and understanding of the bereavement experiences of Gypsies and Travellers, recognising the increased vulnerability to complicate grief responses resulting from the often frequent, multiple intergenerational deaths. These findings highlight the need for specialist community bereavement support resources and services.

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Dedication

For Dad:

My inspiration, my hero, my world

Forever in my heart

Author declaration

I declare that this thesis is entirely my own work and that the work has not been previously submitted wholly or in part for any academic award or qualification other than that for which it is now submitted.

Signature: *Carol Rogers* Date: August 2016

Chapter1: Introduction

'*Who we are shapes how we grieve'* (Niemeyer, 2011:412).

Niemeyer's quote succinctly summarises how grief responses are shaped not only by individual characteristics and experiences, but also by the socio cultural contexts within which we live. Aptly conveying how the cultural influences of '*being a Gypsy / Traveller'* shape their individual bereavement experiences.

This study explores the experiences of bereavement and loss amongst Gypsy and Traveller families in England. The motivation for the research is based on the significant anecdotal evidence (and limited statistical data) which has highlighted the impact of bereavement as a significant health concern for Gypsies and Travellers. Studies by Parry et al (2004), Brack and Monaghan (2007), Greenfields (2008) and Cemlyn et al (2009) all suggest that members of these communities are experiencing high levels of complicated and prolonged grief as a result of the considerably higher levels of suicide, maternal and infant mortality, miscarriage and stillbirth that are found in their population when compared with wider Western society.

It is well evidenced that complicated or prolonged grief (defined as grief that exceeds normative socio-cultural expectations for the adaptation to loss, Granek, 2014), resulting from multiple bereavements can have long term health implications, including depression, anxiety and an increase in risk taking behaviours including alcohol and substance misuse. (Niemeyer et al 2001). These behaviours are manifested amongst Gypsy and Traveller communities and a cause of concern among the policy community working with them.

The close knit nature of Gypsy and Traveller communities means that the death of a relative is felt with great intensity, articulated by some research participants as an event which they *'never come to terms with'*. The significance of bereavement and loss within these groups

can therefore result in a continuum of loss and grief throughout the lifespan, exacerbated by a lack of engagement with support services which are often seen as unapproachable.

This research aims to gain an understanding of the bereavement experiences of Gypsies and Travellers in relation to the effectiveness of Gypsy and Traveller cultural norms and community practice in managing the process of grief and loss. This study is situated within a phenomenological paradigm, exploring life experiences through the medium of Gypsy and Traveller women's narrative stories to gain an understanding of the impact of bereavement on Gypsy and Traveller families. Initially the research was designed using a psychological approach focusing on individual bereavement experiences, However as it evolved the significance of culture on individual bereavement experiences became apparent, and a sociological perspective became more appropriate.

The rationale for adopting a qualitative approach is that this type of 'sensitive research' is most appropriately undertaken through seeking an understanding of people's perspectives *"within the context of the conditions and circumstances of their lives"* (Ormston, et. al, 2013:22) rather than engaging with a positivist methodology.

The methodology chosen enables the participants' voices to be heard and permits more nuances than would a survey based positivist methodology, reflecting both the sensitivity of the research subject (Liamputtong, 2007; Oldfield, et al, 2012), and respecting the vulnerability of Gypsies and Travellers as a minority ethnic group (CRE, 2006). All these factors decrease the power differential between the researcher and the researched (Allmark et. al. 2009; Oakley, 2005). The use of a narrative approach allows both the researcher to explore how participants construct their behaviours and identities within communal settings and also permits the participants to control the amount of information shared when telling their stories (Mitchell & Egudo, 2003; Valentine, 2008). This is an important consideration given the potential sensitivity of bereavement as a research topic (Lee, 1993; Stroebe et al, 2003). Thus ethical considerations and sensitivities in maintaining the wellbeing of the

participants was paramount in the choice of research approach (Allmark et al, 2009). The need for this study and the uniqueness of this research lies in the fact that the literature review has found that despite references to the high levels of bereavement and complicated grief within the Gypsy and Traveller communities impacting on health, the main research focus of studies on these groups is on the delivery of accommodation, health and education (Parry et al 2004; Richardson et al 2007, Cemlyn et al, 2009).

There are very few studies focusing on death and bereavement in Gypsy and Traveller communities. Of those found, these are overwhelmingly undertaken in Ireland rather than the UK, and there is prevalence of studies focusing on death by suicide such as the Nexus (2006) research carried out in Ireland with the relatives of Traveller suicides and Walker's (2008) quantitative study of the prevalence of suicide in the Irish Traveller community in Ireland. The outcomes of the latter study illustrate the excessively high incidence of suicide within the Irish Traveller population in Ireland, something which is anecdotally believed to be replicated in the UK but which has not yet been studied. In addition, Brack and Monaghan's (2007) research (also in Ireland) emphasised high mortality rates in the Irish Traveller population resulting from a range of other factors such as alcohol and substance misuse and accidental deaths, factors which are all identified in the narratives of the women interviewed in this study.

The Irish studies add further endorsement to the anecdotal evidence of high mortality rates amongst Gypsy and Traveller populations found in Parry et al's (2004) report into the health status of Gypsies and Travellers in the UK and to the recommendations made in the Equality and Human Rights Commission Report (Cemlyn et al 2009) which suggests the need for further research into bereavement within Gypsy and Traveller communities.

Other than the three bereavement focused studies in Ireland (of which much of the evidence is statistically based) and Williams' (2003) research with the Manus Gypsies (living and travelling in France) no other reports were found. There is no evidence that a qualitative

phenomenological study of this type exists in the UK suggesting that this current research is the first in-depth study of the bereavement experiences of Gypsies and Travellers in this country. Thus whilst there is official Department of Health recognition of the poor health and high mortality rates in Gypsy and Traveller communities (Gill et al, 2013; Wemyss, Matthews & Jones, 2015), the prevalence and impacts of bereavement remain understated and largely unrecognised for these ethnic groups. Nonetheless the continued rate of excessive premature deaths amongst these populations is tragically evident as in a recent Traveller site fire in Ireland in which ten members of one extended family, including five children under the age of ten, died (BBC news, 2015).

Research aims

The research aims to:

Gain an understanding of the cultural norms and community practices influencing the bereavement experiences of Gypsy and Traveller families.

The study explores the impact of bereavement on individuals and wider family members with consideration given to family structure, gender roles and responsibilities enabling the identification of the specific culturally mediated experiences of Gypsies and Travellers. Attention is given to the close cognate kinship and collectivist nature of Gypsy and Traveller communities, and how bereaved individuals are supported in both a family and community context given that death and loss are not typically openly discussed within this ethnic group.

Based on consideration of the above, as the study evolved the following objectives have developed to provide the framework for the research:

- *To identify whether the experience of bereavement has a long term impact on Gypsy and Traveller life experiences (e.g. impacting on expectations of further loss, attitudes towards family members and relationships).*

- *To explore the extent to which community members feel that membership of a close-knit family and community with explicit cultural norms of bereavement and grief offers effective support for managing the processes of loss or potentially exacerbates the risk of long-term complicated grief.*

Chapter 2: Literature Review

Introduction

The literature used in this review has been chosen to provide a framework to situate the bereavement experiences of Gypsy and Traveller families within their own culture and traditions, framed against bereavement in the wider socio-cultural context, aligning the interconnectedness of family, community and society with the phenomenological context of the research study.

The opening quote of this thesis suggests that '*who we are shapes how we grieve'* (Niemeyer, 2011:412). This underpins this research with the literature review focusing on both personal and socio-cultural factors that are particularly pertinent to the cultural norms and community practices of Gypsies and Travellers. Part one of the review begins with an overview of the development and change in the place of death and bereavement in mainstream western society, The review also considers cultural variations in the perception of and management of death rituals and bereavement support, before focusing on factors that influence individual experiences and expressions of grief, and specific issues that impact on bereavement in Gypsy and Traveller families and communities.

Part two of the review will focus on common issues arising from existing research findings relating to the culture and life styles of Gypsies and Travellers; including death ritual and belief, political influences and the impact of polices on aspects of lifestyle such as accommodation, health and economic issues. In addition consideration will be given to the widespread prejudice and discrimination experienced by Gypsies and Travellers and the impact of this on their lifestyles and willingness to engage with external agencies who could potentially offer bereavement support.

The starting point for the literature review provides definitions for the key terminology relating to bereavement used throughout the study.

Part 1: Contextualising Death, bereavement and grief

There are four key terms associated with death these being bereavement, loss, mourning and grief. To ensure clarity for the reader the following definitions are used within this study.

Bereavement

Bereavement is an overarching term relating to the experience of death and loss. Derived from the Anglo Saxon word *'berifan'* meaning to be robbed of something precious the term summarises how the death of a significant person feels to the individual experiencing that death (Oxford Dictionary, 2016). Thompson (2012) highlights that the literal meaning, '*to be robbed'* does not specifically refer to loss through death but can also include a broader range of losses, as discussed later below when defining loss. Nevertheless bereavement has become the general term associated with the death of a significant person in an individual's life.

Bereavement is defined by Silverman (2000:24) as the '*state of having experienced loss',* whereas Worden (2003:10) describes it as '*defining the loss to which the person is trying to adapt'*. Stroebe & Schut (1998:7) suggest that bereavement is *'the situation of a person who has recently experienced the loss of someone significant through that person's death'.* more recent definitions include references to the impact on both physical and mental health and wellbeing such as in Van-der-Houwen's (2010:169) description of bereavement as a *'stressful life event associated with excess risk of mortality and with decrements in both physical and mental health'.*

In summary bereavement is the experience of loss following the death of a significant person which by its very nature is also a time of adaptation and change, disrupting the continuity of normal life and which may affect the health and wellbeing of some individuals.

Loss

Bereavement and loss are often used as interchangeable terms when discussing death, with loss referring to no longer having something or someone with whom there was a strong emotional connection (Thompson 2012).The concept of loss often extend beyond the physical and emotional loss of a person and include, the wider socio-economic and environmental changes following a death. These secondary losses can include the loss of home, income, schooling and friendships as bereavement often changes the patterns of life for the remaining family members creating a multiplicity of loss in differing contexts (Doka & Martin, 2010; Parkes & Prigerson, 2010).

Mourning

Mourning refers to the social structure and rituals that support the grief process. Mourning is the *'social expression or acts expressive of grief that are shaped by the practices of a given society or cultural group'* (Stroebe et al 2001:6).

From a psychological perspective mourning is defined as a healing process that the bereaved person goes through adapting to their loss and to life without the deceased (Engel, 1961; Silverman, 2000; Worden, 2003, 2009). This standpoint maintains an individual focus with little differentiation between grief and mourning. In contrast a sociological stance defines mourning from a socio-cultural perspective, as the socially expected behaviours and rituals shaping the socio-cultural expression of grief (Stroebe, 2009; Walter, 2008, 2010). Thus mourning is the socially defined and external focus or *'public face of grief'* (Parkes, 1988:54).

Grief

Grief is the emotional or affective response to bereavement and loss that has both physical and psychological consequences that may impact on health (Raphael, 1984; Stroebe, 2009; Walter, 1999). Definitions of grief have been shaped by the prominent theoretical position of the time; as such medical models present grief as an illness or disease and defined as '*a*

departure from the state of health and wellbeing' Engel (1961). Moreover recent theoretical perspectives recognise that grief is the emotional process following bereavement, as suggested by Silverman's (2000:24) definition of grief as '*the physical and emotional journey a person experiences whilst coming to terms with their loss'.* Hence current theories recognise normative or uncomplicated grief as a life process and as a time of transition, change and adaptation for the majority of people; whereas a minority may experience complicated or prolonged grief that needs medical intervention (Niemeyer, 2011; Worden 2009).

The discourse surrounding grief is far from straightforward as is evident from the differing perspectives considered whilst defining grief in the previous paragraph. A brief definition is not sufficient to explain the complex discourse of what constitutes normal and complicated grief, therefore a more detailed discussion is included here as differentiating between normative and complicated grief responses was fundamental to this study.

Normal & Complicated grief

Normal or uncomplicated grief refers to the common feelings and behaviours following bereavement (Worden, 2009). The majority of bereaved people will experience 'normal' grief reactions, which include a wide range of physical, emotional and behavioural reactions to loss. Common physical reactions can include; headaches, nausea, insomnia and loss of appetite. Emotional responses include; sadness, anger, guilt, anxiety and for some relief (particularly if the death followed significant illness or if there was a complicated relationship between the deceased and bereaved). Cognitive responses to grief include disbelief, confusion and an obsession or pre-occupation with the deceased and behavioural responses can include sleep disruption, social withdrawal, and increased use of alcohol or substance misuse (Worden, 2009; Thompson, 2012; Granek, 2014). When combined these reactions to loss demonstrate the complexity and multifaceted nature of grief.

Normal grief reactions become less severe over time and although there is no set timescale to how long grief should last it is usually between six months and two years after the loss that the bereaved person is able to move forward with their life (National Cancer Institute, 2013). Normative grief patterns are defined as being relational to the context of the loss, with grief responses dissipating over time as adjustments are made to life without the deceased (Fox & Dayle-Jones, 2013). However some bereaved individuals become 'stuck' within the grieving process and unable to move on with their lives (Cruse, 2015). For these individuals there are often increased risk factors associated with prior life experiences that increase their vulnerability to complicated or prolonged grief.

Complicated grief is the umbrella term used to encompass a number of reactions to grief, sometimes also known as prolonged, pathological, traumatic or chronic grief (Parkes & Priggerson, 2010; Rando et al, 2012). Approximately 10% of bereaved individuals experience complicated grief reactions which can often lead to long term health problems (Lobb, 2010; Shear et al 2011; Wimpenny, 2006)

Complicated grief can be defined as the continuation of grief related symptoms beyond the timespan which is considered normal for adaptation to bereavement and loss (Lobb et al 2010). However, it is important to remember that there is no universal norm; patterns of grief both normative and complicated will be defined by socio-cultural mores and the individual life experiences of the bereaved (Granek, 2014). This is recognised in Stroebe, Schut & Stroebe's (2007) description which identifies complicated grief as patterns of grief that differ in the intensity and time span from cultural and societal norms for grief reactions.

Complicated grief patterns can occur as a result of increased vulnerability and personal risk factors, these include; those with anxious or avoidant attachment relationships, high dependency on the deceased, lack of social support and the mental health of the bereaved (Parkes, 2006; Van-der-Houwen et al, 2010). Furthermore the type of loss can impact on responses to grief with traumatic deaths such as suicide or sudden and premature deaths

increasing vulnerability to complicated grief (Shear et al, 2011). Thompson (2012) suggests four categories of loss that can result in complicated grief; the first is cumulative grief or multiple losses over a short period of time, second is the multiple loss of a number of people at the same time. Third are sudden or unexpected losses and finally disenfranchised or socially unrecognised losses. Hence complicated grief is often a result of a death that is outside of expected societal norms.

Doka describes disenfranchised grief as '*the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publically mourned, or socially supported*' (Doka, 1989:4). Hence disenfranchised grief refers to deaths that are socially awkward or stigmatised such as suicide, substance related, miscarriage, stillbirth or familial estrangement, or where individual grief responses do not meet with the socio-cultural expectations of mourning rituals (Kalich & Brabant, 2006). There are primarily three types of disenfranchised loss; first, the relationship between the deceased and bereaved is socially unrecognised or secret, for example same sex relationships, so that the true nature and intensity of grief cannot be expressed. Second the loss is disenfranchised; for example survivors of bereavement by suicide can find their grief constrained by the social stigmas attached to suicide resulting in a lack of social support. Last grievers can be disenfranchised through stereotypical assumptions; children are often considered too young to understand and perceived not to grieve, so their grief is unrecognised. Similarly people with learning difficulties are often considered not to grieve due to lack of cognitive understanding. The elderly can also be disenfranchised by the assumption that they are likely to have experienced numerous losses across their lifespan so are less affected, or used to loss and grief (Parkes & Priggerson, 2010; Thompson, 2012).

'Complicated grief is complicated' (Rando et al 2012:253), as patterns of grief seen in complicated and prolonged grief often mirror the symptoms of anxiety, severe depression and post-traumatic stress (National Cancer Institute 2013). Hence there is a fine line between bereavement related depression and major depressive disorders (Fox & Dayle-

Jones, 2013). Moreover bereavement, particularly traumatic bereavement increases the risk of depressive disorders including post-traumatic stress syndrome (PTSD) (Stroebe & Schut 2005).

The complexities of defining complicated or prolonged grief and depressive disorders are further exacerbated by the controversial debate relating to the clinical definitions and assessment criteria used to identify major depressive disorders in the Diagnostic and Statistical Manual of Mental Disorders (DSM), compiled by the American Psychiatric Association (APA). Although DSM is not formally used in the UK, the World Health Organisation's International Classification of Diseases is used by the NHS; the DSM remains influential with both bereavement theorists and practitioners (APA, 2013; Penny, 2013).

Previous versions of DSM criteria have had a bereavement exclusion clause that prevented depressive disorders being diagnosed within two months of bereavement unless the bereaved express suicidal thoughts or psychotic symptoms (APA 2013). There has been significant debate surrounding the removal of the bereavement exclusion clause in the latest version DMSV. The argument for the removal of bereavement exclusion criteria centres on the concern that grief may act as a mask for depression in some individuals, delaying diagnosis and support. Thus removal of the exclusion criteria can prevent depressive disorders being overlooked. However there is further concern that the removal of the exclusion criteria jeopardises the recognition of bereavement and grief as a normative life experience. There is then juxtaposition between overlooking depressive disorders but also over pathologizing normal grief reactions. Nonetheless there is clearly a need to be able to distinguish between normal grief reactions, complicated grief and depressive or other mental disorders (Shear et al, 2011a).

Grief is a normal life experience whereas depression is often considered an illness and although there are similarities in some symptoms there are also distinct differences between the two (National Health Service (NHS), 2015). Symptoms common to both complicated grief

and depression include yearning and preoccupation with the deceased, separation distress, sleep disturbance and social withdrawal (Lobb, 2010). The differences between complicated grief, depression and PTSD are in the psychological approaches to the loss. Complicated grief responses to yearning and preoccupation with the deceased are focused on feelings of sadness, loss and the deceased, whereas for PTSD reoccurring thoughts and images of the trauma are prominent, and in depression thoughts are focused on the self, hopelessness, low self-worth and sometimes suicidal tendencies (National Institute for Clinical Excellence (NICE), 2009). Moreover the emotional intensity of grief comes in waves, with the bereaved oscillating between sadness and positive memories of the deceased experiencing both loss but also some adjustment to restoration of normal routines (Stroebe & Schut 1999), whereas in depression there is a constant negativity (APA, 2013).

Klass (2013) also reiterates the complexities of grief and depression by discussing how despite recognising continuing attachment to rather than detachment from the deceased, contemporary views on grief theory and practice remain recovery orientated. Klass argues that a recovery focused approach does not recognise the long term impacts of grief. Klass uses the term *'grief depression'* to differentiate between grief and clinical depression, summarising grief depression as the long term sorrow or sadness experienced by the bereaved that remains long after they have adjusted their world view and accepted life without the deceased and seemingly recovered from their grief. Klass, similarly to Tonkin (1996) suggests that grief does not disappear but that the bereaved grow around their grief retaining their sorrow or grief's depression. Furthermore Granek's (2013) findings from an online study of the phenomenological experiences of grief reported that just over a quarter (27%) of respondents never returned to pre-loss feelings of normality, a further 27% stated feelings of normality one to two years after bereavement with another 27% stating that recovery may take many years, if at all. Only 11% of respondents reported no symptoms of grief and a return to normality six months after their loss. These findings are significant given that the diagnosis of complicated grief or depressive disorders is considered six

months post loss. Granek's (2013) findings confirm the complexities of grief and highlight the challenges faced when trying to differentiate between complicated grief and depression and the importance of recognising the determinants of grief influencing each bereaved individual's responses to grief. It is the predisposing experiential factors that impact on whether the bereaved experience normal or complicated grief reactions or depression.

Reflecting on the complexities of grief it is clear that the circumstances and mode of death have a significant impact on grief responses of the bereaved. Whilst traumatic and premature deaths can increase vulnerability to complicated grief reactions it is important to remember that many deaths are peaceful or offer a release from pain and suffering.

Summarising the definitions for the purpose of this study, bereavement is the term generally applied to the loss of someone by death with whom there was a significant relationship and the impact that the loss has on the lives of family and friends. Grief refers to individual physical and emotional responses to loss and mourning to the wider cultural or societal behaviour, rituals and process of adapting to life without the deceased. The focus of the discussion will now consider the differing attitudes, behaviours and practices relating to death in western society before comparing these with other cultural approaches to death.

Death and society

> *'Every society has a way of dealing with the influence of the dead on the lives of the living'* (Silverman 2000:11).

Death has been defined as '*a great leveller'* affecting all communities equally regardless of age, gender, social class, or position in society (Field et al, 1997:1). However, in reality the circumstances of death and dying are often influenced by the experiences and inequalities of life (Marmot, 2010; Straudt & Block, 2012). Although death is universal, the way in which individuals, families and societies deal with loss and grief differs greatly as a life experience embedded in their socio- cultural world (Howarth, 2007; Walter, 1999). Moreover all families

and societies have cultural norms that determine their patterns of behaviours, including death rites and expression of grief. Whilst at times of distress these norms often become prevalent, societies and cultural groups today are not generally homogenous so there will be class, gender and generational variations to bereavement and expression of grief (Walter, 2008). Thus societal influences, life experiences, belief systems and rituals will determine the impact of the dead on the living,

Silverman's (2000) quote above, reiterates the influential place of death in society, therefore the review will now consider how western attitudes to death and bereavement behaviours have changed over time. Consideration will also be given to other cultural approaches to help situate the death and bereavement behaviours of Gypsies and Travellers.

Attitudes to death and dying in western society

The place of death and dying within western societies has changed significantly over time, linked to the growth of medicine and public health awareness (Illich, 1990). In the middle ages attitudes changed from a fatalist and religious view that death was inevitable and determined by God, to the recognition of death as a natural life event, leading to '*death becoming a force of nature with which to do battle'* (O'Gorman,1998:129). Later in the eighteenth century industrialisation, wealth and societal change brought an increased awareness of health and longevity and the use of medicine to delay death. This medical health focus continued to gain momentum throughout the nineteenth and twentieth centuries with death removed from society into hospitals where the boundaries of life and death blurred and resulted in the removal of death from public life (Aries, 1974; Howarth, 2007; Walter, 1994).

It is evident that the medicalisation of death has played a significant part in the removal of death and death ritual from the public to private domain. In fact it is arguable that during this period medicalisation provided a form of social support and control replacing the role previously held by religion in society (Gabe et al, 2004). Thus the management of loss and

grief shifted from religious and community support to that of the medical professional. Furthermore Aries (1981:560) proposes three significant reasons for the shift of death from the public to the private domain in modern western society. Firstly that '*society banished death',* suggesting that following the two world wars the enormity of grief and loss led to removal of death from society in an attempt to recover from the war years. Secondly the loss of public mourning as a consequence of the whole society being in mourning, and thirdly, again resulting from the wars, medical intervention and hospitalisation shifted the focus of death from home and the fatalist religion based view to the medical science based model of today where death has, '*moved from home to hospital' (*Silverman, 2000:12).

This shift from home to hospital created a physical separation of the living and the dead which has been further extended with the development of the role of the professional carer now commonly taking the place of family in caring for the dying (Aries, 1974; Walter, 1994). Thus the medical model of modern western society developed a clinical and impersonal approach to death and dying in a sterile environment cared for by strangers, in contrast to historic and collectivist cultures where the dying are comforted and cared for by family in their home environment (Aries,1974). Not only has the modernist approach seen a physical separation between the individual and their family, but has also isolated grief and mourning to a privatised and individual rather than socially supported process, further exacerbating the denial of death in the nineteenth and twentieth centuries (Hockey et al, 2001; Walter,1994, 1999).

Alternatively Elias (1985:8) attributes the denial of death to the increasing life expectancy of modern society, proposing that increasing longevity and life expectancy means that individual mortality is largely ignored, so '*as life grows longer death is forgotten'*. Consequently death in modern western societies has been managed by medical professionals who to an extent have removed responsibility for death from the individual and society resulting in death being a taboo subject, feared and hidden on the margins of society (Aries, 1974, 1981; Field et al, 1997; Niemeyer, 2011).

Moreover during the latter part of the twentieth century a growing sociological interest has seen an increasing discourse relating to death, grief and bereavement (Giddens & Sutton, 2013). Sociologist Tony Walter has been at the forefront of this dialogue postulating that although the dead have been marginalised they remain very much present in society represented by a generic public and media focus on death, demonstrated by the media obsession with dead celebrities and public memorialisation of death sites with floral tributes (Walter 2008).Therefore whilst death remains a taboo, feared, and an uncomfortable conversational topic, it does as Walters (2010) suggests remain ever present in daily life. Indeed he attests that the latter part of the twentieth century has seen a *'revival of death'* citing the growth of hospices and bereavement support services as instrumental in this process (Walter1994). In contrast Parkes (2011) argues that the revival of death is a result of the increasing research interest in death studies and medical interventions that prolong life.

This has led to a changing focus of medical care from a purely clinical and physical care based approach to death, to the inclusion and consideration of the emotional and mental health needs of both the dying and the bereaved. This has created a plethora of theories and models of death, bereavement and grief that seek to rationalise the medicalisation of death and juxtapose bereavement as a normative life process but also as a debilitating experience that has both physical and mental health implications for some individuals (Bowlby, 1980, 1981; Freud, 1917; Kubler-Ross, 1969; Van-der-Houwen et al 2010).

Grief is not a linear process with concrete boundaries but rather a composite of overlapping, fluid phases that varies from person to person' Stroebe (1993:23).

The above quote by Stroebe refers to the personal process of grief but also reflects the development of the discourse and theories pertaining to grief. Driven by a particular paradigm, psychological, medical and more recently sociological, theories and models of grief have shifted from the traditional loss orientated approach focused on letting go of the deceased by severing attachment bonds , to current contemporary theories centred on loss as a time of transition and change recognising grief as an individual journey rather than a

generic linear or stage orientated process (Parkes, 1988; Parkes & Prigerson, 2010; Ribbens–McCarthy,1996; Thompson 2012).

Contemporary grief theory disputes the premise of severing attachment bonds, focusing instead on continuing bonds with the deceased. Walter (1999:106) argues that: *'The purpose of grief is not to break bonds with the deceased but to integrate the dead into the survivor's on-going life'.* This philosophy of continuing rather than severing attachments underpins current theories and models of grief including Klass, Silverman and Nickman's (1996) continuing bonds theory and Stroebe and Schut's dual process model. These theories recognise that grief is an individual process determined by the relationship and attachments between the deceased and survivor with grief work focused on supporting the process of relationship change.

Stroebe and Schut's (1999) dual process model suggests that the bereaved individual oscillates between a loss orientation process where the bereaved reflects back on life with the deceased and a restoration process which looks forward to adapting to life without the deceased. This model is particularly relevant when considering gendered and children's grief. The dual process model reflects the differences in male and female grief patterns as women tend to be loss orientated and men restoration oriented, Doka and Martin (2010) identified differing gender patterns of grief, (gendered patterns of grief are discussed later in the literature review on page 36) (Stroebe & Schut, 2010). When considered in relation to children's grief responses the dual process model reflects how children dip in and out of grief and normative activity as they try to understand loss and adapt to a changed life world (Mallon, 2011).

Similarly continuing bonds theory is framed around adapting to life without the deceased through memorialisation, using memories to create internal representations of the deceased, to maintaining a continuing bond and relationship with the deceased (Klass, Silverman & Nickman, 1996). Unlike the established theories of grief which advocate that the resolution of

grief requires breaking attachment bonds with the deceased with the failure to do this resulting in a pathology of unresolved grief, continuing bond theory proposes that it is healthy to hold on to memories and attachments to the deceased. The continuing bond or relationship with the deceased is maintained and integrated into the survivor's ongoing life experiences meaning that *'the deceased are both present and not present at the same time'* (Klass, Silverman & Nickman1996:351).This approach asserts that some form of inner representation or memory of the deceased remains constant throughout the survivor's lifetime suggesting that continuing attachments to the deceased are normal rather than abnormal as earlier grief theories have postulated.

Attig (2011) concurs that grief facilitates the process of change in the assumptive world of the bereaved but refers to the adjustment to loss and meaning making as '*re-learning the world'.* He summarises the challenges facing bereaved individuals as they embark on processing their grief and redefining their lives without the deceased:

> *We need not break bonds with the deceased but instead redefine those bonds and their places in our lives. Rather than challenge us to separate from the dead, their deaths challenge us to maintain meaningful connection and to integrate redefined relationships into our necessarily new life patterns* (Attig, 2011:74).

Moreover whilst the discourse of how the bereaved manage their grief and adjust to life without the deceased has focused from detachment to integration and redefined relationships Lois Tonkin's (1996:10) model of grief provides an alternative perspective, rather than recovery from grief the bereaved '*grow around grief*'. Tonkin suggests the intensity of grief does not diminish over time, grief stays the same but the bereaved grow around their grief. This model acknowledges that there is no recovery from grief but that new life patterns are developed around it. Tonkin also discusses the '*richness and depth'* that experiencing grief provides in readjusting life, suggesting positive outcomes when growing around grief. For some the transitional process from life before to life after loss affords new opportunities, roles and responsibilities that would not have been experienced prior to the

loss. In this way grief can eventually provide positive outcomes as life is re-learnt (Attig, 2011; Thompson, 2012; Tonkin, 1996).

In summarising this section of the literature review it is clear how socio-cultural trends and development of theoretical frameworks and models of grief have influenced bereavement behaviours. For example, a biologically focused stance considers the health implications of bereavement, hence the view of grief as an illness. A biological perspective suggests that bereavement stress can result in both physical and mental health problems, increasing both morbidity and mortality rates following bereavement (Stroebe & Stroebe, 2001; Van-der-Houwen, 2010). Alternatively a psychoanalytic standpoint bases grief work on the acceptance of death, moving from the continued existence of the deceased to the reality of the loss, readjusting or 'working through' the emotional pain of life without the deceased. Working through or processing grief to enable recovery or adjustment to life without the deceased has resulted in the development of theories, which advocate that grief work following bereavement involves moving through recognised stages of grief, these include denial, anger, despair and finally acceptance of loss ((Kubler-Ross,2009). Inevitably the stage based approaches led to linear and prescriptive interpretations of each stage rather than the flexible and overlapping of stages as the authors intended (Kubler-Ross, 2009Parkes, 1972; Parkes & Prigerson, 2010, Worden, 2009).

Furthermore a psychosocial approach views bereavement as a psychosocial transition where the process of grief aims to adjust the world view from pre to post loss, to realign the external and assumptive world views following loss. The ease of which this process takes place is dependent on the existing world view, the type of loss, previous experiences and the availability of both personal and contextual coping resources that aid adjustment to the world view (Attig, 2011; Carr, 2006; Hibberd, 2013). The complexities of grief and loss mean that bereavement is recognised as one of life's most stressful and significant psycho-social transitions (Parkes, 1988; Parkes & Prigerson, 2010). Psycho-social transitions are defined as events that require major changes to internal assumptive worlds, which have long term

implications and that take place without the opportunity to plan for them (Parkes, 1993). Bereavement transitions require adjustment to significant attachment relationships and to the future life world without the deceased (Shear, 2011). For most people these adjustments are made through the transitional process of grief.

Today contemporary theory has shifted from the traditional theorists' approach of recovery through 'grief work' to continuing bonds and meaning making (adjusting the self-narrative or life story) to come to terms with loss and continue with life, albeit in a different relational context (Niemeyer & Sands 2011; Thompson, 2012). This shift in thinking has moved grief from being considered as an illness or disease from which the bereaved needed to recover (Engel 1961) to being considered as a transition from the life before loss to that after loss and as such a normative life process (Thomson, 2010). Nonetheless despite now being defined as a normal and natural life event both traditional and contemporary theorists agree that grief has a significant impact on both physical and psychological health and wellbeing, blurring the boundaries between health and illness (Parkes, 2011). For some individuals grief has a short term and minimal impact on their daily functioning, health and wellbeing but for others grief creates significant health problems and increased mortality rates (Bowlby, 1980; Parkes & Prigerson, 2010; Raphael, 1984; Stroebe et al, 2008; Thompson, 2012; Worden, 2009)

Given that bereavement is one of the most traumatic life experiences it is not surprising that grief has a significant and often debilitating effect on the health and wellbeing of the bereaved (Thompson, 2012; Van-der-Houwen et al 2010). For example during the Romantic era of the eighteenth century grief is recorded as a cause of death, with the bereaved commonly referred to as '*dying from a broken heart'* (Parkes, 2002, 2010; Parkes & Prigerson, 2010; Stroebe et al, 2008). Whilst this may seem overly dramatic and perhaps more aptly found in a romantic novel there is evidence of increased mortality rates in the bereaved particularly within the first year of loss. Most commonplace is spousal bereavement, with widowers being most at risk within the first six months following

bereavement (Bennett et al, 2003; Bowlby, 1981; Parkes, 1972; Stroebe & Stroebe, 2001). Bereavement suicide also poses an increased risk particularly for men in the first year of loss where the cause of death was suicide (Ajdacic-Gross et al, 2008; Stroebe, Schut & Stroebe, 2007) and an increased mortality risk is also prevalent for parents following the loss of a child (Harper, O'Conner & O'Carroll, 2011). Today the increased mortality rates found in the first months and years following a significant loss are attributed to physical illness such as heart disease, psychological distress and secondary losses such as loneliness, lack of social support and changes in socio-economic circumstances rather than a metaphorical broken heart (Stroebe, Schut & Stroebe, 2007).

Cultural approaches to death

The literature review so far has focused on the perceptions of death within western society. However; whilst death and grief are universal, the place of the dead in society, mourning rituals and the manifestations of grief vary greatly across cultures (Field et al, 1997; Gire, 2014; Neimeyer et al, 2014; Thompson, 2012). Defined as '*the attitudes and behaviour characteristics of a particular social group or society'* (Oxford dictionaries 2013), culture shapes the behaviours of societies including expressions of grief and mourning rituals, thus providing a framework and timescale for bereavement behaviours (Niemeyer 2011). Religion also plays a significant part in defining these behaviours and although religion is not in itself cultural it does interact with culture influencing mourning rituals and behaviours (Garces-Foley 2005). Hence cultural traditions, values and behaviours, which may include religious belief, set the boundaries for the management of bereavement and mourning (Neimeyer et al, 2014). Therefore as Walter (1999) advocates society polices bereavement, determining the acceptable range of emotional expression and mourning behaviours. Niemeyer (2001) concurs with this view suggesting that personal bereavement experiences are influenced by wider societal expectations. Klass and Yin-Man-Chow (2011) develop this idea further by suggesting that the cultural policing of grief falls within two aspects, the expression of emotion and how continuing bonds with the deceased are maintained.

There are wide cultural variations to how the two aspects, emotional expression and the continuing bonds or integration of the dead within society are expressed through funeral rites and expressions of grief. In fact Stroebe and Schut (1998) assert that while there are collective emotional reactions to grief, the strength of cultural belief and behavioural expectation can override personal reactions. This is evident when considering how differing societies' manage bereavement. For example mourning rituals in Western societies are differentiated by personal belief, either religious or increasingly following a humanistic approach (Hockey, Katz & Small, 2001). Funerals are intimate family affairs where grief is expressed privately rather than publically. This individual approach may appear to contradict the assertions above that cultural expectation overrides individual behaviours and whilst the diversity of Western culture appears to provide individual choice the stoic and restrained public expression of grief is an overriding cultural behaviour.

In contrast in collectivist society's individual grief is less important with mourning focused on fulfilling responsibilities to both living and dead family members (Rees, 2001). Examples of these whole community or collectivist approaches can be found in many First Nation cultures such as Native Americans and Australian Aborigines where there are often elaborate mourning rituals that either separate or continue bonds between the living and the dead, such as in the Native American Navajo tribe who limit the acceptable period of grief to four days with minimum expression of grief, thereafter the bereaved are expected to resume normal life and not mention their loss or speak the name of the deceased again. Underpinning this is the belief that excessive grief and referring to the deceased would prevent the spirit moving into the afterlife and that malevolent spirits prevented from moving on are harmful to the living (Stroebe & Schut; 1998). Similar examples are found in the beliefs of Australian Aborigines where funeral rites are elaborate and focused on separation of the living and the dead (Gire, 2014).

Conversely alternative beliefs that maintain the bonds between the living and the dead through the transformation of the deceased into ancestors are also found in a number of

cultures including Japan. The Japanese retain deep ancestral ties through the Shinto religion and belief that family is sacred. The continuing bond between living and dead is maintained through relationships where the dead retain an active presence in the lives of the living and as such there is no divide between the living and dead and relationships maintained through reciprocity where the living care for the dead through elaborate ceremonies and the dead watch over the living. The family focus of respect and continuing care for the deceased in the Japanese ancestral approach is designed to maintain family relationships across the life death boundaries. Thus grief is a series of collective ceremonies rather than as an individual internal response to loss (Bryant & Peck 2009; Parkes et al, 997; Valentine, 2009).

Interestingly Valentine's (2009) study comparing bereavement in Japan and the UK found similarities in responses to grief despite very different cultural approaches to death. Finding that there were some elements of diversity and individualism within the interdependent and collectivist Japanese culture just as there were examples of interdependence and continuing bonds within the UK sample. The study's sample consisted of twenty five interviews with bereaved individuals, ten men and fifteen women from Bath in the UK and seventeen interviews, thirteen women and four men from Tokyo in Japan, all were bereaved of close family members. Valentine suggests that in post-industrial Japan which is more similar to contemporary Western society with comparable cultural diversity, individuals are no longer constrained by traditional cultural conventions but are more likely to adjust these to reflect personal circumstances and experiences. So whilst there are clearly cultural differences in either separating or maintaining bonds with the dead across cultures as Valentine (2009) illustrates the similarities may be greater than expected.

Laurie and Niemeyer's (2008) study of African American bereavement experiences is particularly pertinent as there are some cultural similarities with Gypsies and Travellers in that both live within, but on the margins of mainstream white societies experiencing poverty,

racism and oppression (Laurie & Niemeyer, 2008; Ryder, Cemlyn & Acton ,2014). Both groups also live in extended family kinship communities.

The study noted that African Americans experienced lower life expectancy and higher premature losses of parents, spouses and children than their Caucasian American counterparts. Furthermore they were less likely to seek professional medical or mental health support or seek professional help following bereavement, turning instead to community social support networks. Inward facing community support highlighted community resilience and a cultural expectation '*to be strong'*. When considered in the context of bereavement Laurie and Niemeyer's findings suggest that extended kinship relationships resulted in a greater intensity of grief for both immediate and extended family and community members and very strong continuing bonds with the deceased. In addition they were less likely to talk about their losses. However the study's findings asserted that being surrounded by extended family and drawing on strong religious beliefs means that the bereaved *'gain strength from practical support',* such as the provision of food, religious and spiritual rituals and by having people around them (Laurie & Niemeyer,2008:186). Despite the resilience and strong kinship relationships noted in bereaved African Americans they experienced higher levels of complicated grief symptoms than their Caucasian counterparts. The findings of this study echo those of Laurie and Niemeyer's study with Gypsies and Travellers experience similar life expectancy, experiences and bereavement behaviours.

These examples both highlight the cultural variations in bereavement behaviours and also identify the theoretical perspective of either breaking bonds or continuing bonds with the deceased. Interestingly the examples of First Nation states which break bonds with the deceased are linked to spiritual beliefs that the dead will cause harm to the living, thus a fear of the dead leads to short mourning periods severing ties to the deceased. In contrast the religious beliefs and rituals of Japan promote very strong continuing bonds with the deceased. Klass, Silverman and Nickman (1996) cite an example of a research study similar to that of Valentine (2009) comparing Japanese and British widows in 1969, the results

found a better adjustment to loss in the Japanese widows who maintained a strong continuing bond with the deceased whereas at that time breaking bonds was the predominant practice in Britain. Whilst some cultures and societies have very clear traditions and beliefs about severing ties or continuing bonds with the deceased the picture in Western societies is more complex. In part as a result of the individualistic rather than collective societal approach but also as science and medicine prevail over traditional beliefs breaking or continuing bonds with the deceased has fluctuated and changed with the development of differing theoretical perspectives.

In conclusion culture is influential in shaping bereavement experiences. Whilst each culture has its own particular beliefs and rituals underpinned by cultural tradition or religion, there is some continuity in the belief that death is a transition, or journey to some form of afterlife or to reincarnation (Rosenblatt 2008). Elaborate funerals and mourning rituals structure the management of bereavement determining how the dead are perceived within society, marginalised at the edge of society, not quite left behind but not comfortably integrated as in Western society or as highly respected ancestors with strong continuing bonds within both family and society (Gire,2014). Undoubtedly the strength of cultural belief and behavioural expectations will determine how the dead influence the lives of the living, but as Walter (2010:6) suggests '*Individuals are shaped by their culture but not determined by it*'. Thus individual circumstances and experiences will also be prominent in the personal manifestations and management of grief.

Moreover Walters (1994) questions whether the individualistic approach to death of current western society is sustainable without some of the traditional support systems of family and religion. Perhaps the growth of hospice and bereavement support services is the modern equivalent bridging hospital and home care and providing the societal and community support for the dying and bereaved. None the less whilst the place of death may have shifted it remains marginal rather than central to twenty first century society.

In contrast the cultural norms and community practices of Gypsies and Travellers remain family and community orientated, aligning more closely with other marginalised ethnic minority groups such as Indigenous Australians and African Americans, as highlighted in Laurie and Niemeyer's (2008) study, than current western societal approaches to death and bereavement. The literature has identified that unlike western societal approaches to death and bereavement that are predominantly individualistic Gypsy and Traveller cultural morns are family and community orientated, often to the detriment of the individual. Glaskin et al (2008) suggest that stoic attitudes and protective behaviours which appear counterproductive to individual grief responses are in fact based on preserving cultural identity. This is certainly evident in the findings of this research where protecting family is prioritised above individual health and wellbeing. Given that the focus bereavement behaviours is on family and community rather than the individual within Gypsy and Traveller communities the literature review now briefly considers bereavement and grief from a family systems perspective as this is particularly pertinent for this ethnic group.

Family systems theory

Bereavement and grief theory are predominantly focused on grief and the loss of relationship from an individual standpoint with limited attention given to how the loss impacts on wider family relationships and family functioning. Yet the death of a family member has a profound effect not only on individual grief response but also the whole family (Hayslip & Page, 2013; Walsh & McGoldrick, 2013).

Family systems theory is an approach which considers the family unit from a holistic perspective, looking at how each individual member of the family interacts with each other, the organisational structures hierarchies, boundaries and behavioural expectations. Hence individual functioning is interwoven with the behavioural expectations and emotional relationships of the family unit. Families systems consist of a number of subsystems of intergenerational relationships, grandparents, parents and children (Holmes et al 2013).

Bereavement from a family systems perspective starts from the premise that bereavement is a normative life event. Family is central to and shapes the shared experience of bereavement and grief through the adaptation of roles, responsibilities and family functioning (Carr 2006). This adaptation is influenced by the circumstances of the death, family functioning and socio-cultural contexts including poverty, discrimination, religious and community support (Walsh & McGoldrick 2013). By aligning these factors with Bronfenbrenner's (1979) ecological theory the complex nested and overlapping support mechanisms can be identified. Individual support is gained from immediate family and close associates (microsystem). Family support networks will include extended family, religious and community supports (macrosystem), in turn these will be influenced by the overarching socio-cultural contexts within which the family live (the Chronosystem)(Bronfenbrenner, 1979, 2005).

Complications to the process of family adjustment to loss can result from premature or untimely deaths including the loss of a child, or early parental death and early widowhood. In addition the complex nature of family structures today, ranging from single parent families to those which include multiple relationships and blended families, or those living in extended family or kinship communities may complicate processes or the overall picture.

Walsh and McGoldrick (2013) advocate a four task approach that supports family transitions and adaptation following bereavement. Task one refers to reaching a shared acknowledgment of the death and loss. Well-functioning families will adapt with a heightened appreciation of loved ones, whilst family members who are unable to accept the reality of loss may become withdrawn and resentful of those who have accepted the loss and are moving on with life. Task two involves a sharing of the experience of loss and grief, gaining comfort and support from family through rituals and memorials. Task three concerns reorganisation of the family system, adjusting to new roles and relationships to maintain stability of family functions. Finally task four relates to reinvestment in other relationships

and the continuity of life following loss. These tasks are not unique but align with Worden's (2009) tasks of mourning.

Factors affecting grief

Individual predispositions to grief responses are influenced by culture, personality and life experiences which in turn affect the degree to which bereavement impacts on health and wellbeing (Van-der-Houwen et al 2010). The factors affecting grief reactions are multifaceted and include; socio-cultural grief and mourning rituals, expressions of grief, religious or spiritual belief and family as a support system (this includes the degree of openness or denial of loss within the family). Other determinants of grief include the nature and circumstances of the death, gender, the relationship between the deceased and the bereaved, personality traits and prior bereavement experiences (Asaro & Clements, 2005; National Cancer Institute, 2013). Worden (2003) refers to these factors as the mediators of mourning. The factors most pertinent to the research findings are discussed here, these include, cultural trauma and bereavement, resilience to loss, gender and mode of death. There is not the space within this review to consider the impacts of all modes of death on grief reactions in detail so only sudden traumatic deaths, and suicide have been discussed as these are the particularly prevalent within Gypsy and Traveller communities.

'How people die remains in the memory of those who live on' (Dame Cicely Saunders cited DH 2008). The above quote is a poignant reminder of the impact of death on the bereaved. A peaceful death may bring some comfort, whereas sudden or traumatic loss can have a lasting effect on and complicate grief responses.

Sudden, traumatic death

Sudden and traumatic death, particularly deaths by human agency such as murder or suicide are some of the most difficult types of death for the bereaved to come to terms with (Chapple et al, 2012), but are the most prevalent modes of death in those under the age of forty with the exception of death from cancer (Barlé, Wortman & Latack, 2015). The office of National Statistics (ONS) (2014) mortality data suggests that cancer is the most common cause of natural death accounting for 29% of deaths whilst the leading causes of sudden death is heart attack which is responsible for 27% of deaths. 'Other' causes of death accounted for 29% of deaths; this category includes suicide, homicide and accidental deaths. These figures demonstrate the high numbers of sudden and unexpected deaths, either through natural causes such as a heart attack or by unnatural causes such as accidental or intentional homicide or suicide deaths.

Sudden or traumatic deaths, such as violent deaths, homicide and suicide create unique challenges for the bereaved that are not found in natural deaths by challenging basic life assumptions of safety, security and social justice (Barlé, Wortman & Latack,2015). Any loss of a family member changes the family dynamic, but homicidal deaths impact on family systems and functioning disrupting daily routines and the growth and development of both individual family members and the family as a whole. Traumatic deaths increase the risk of family separation as a result of the increased pressure on family systems to continue to function effectively as a family unit (Asaro & Clements, 2005). Each individual's grief will differ and be affected by the family's capacity to communicate and support each other. In addition the loss of the deceased will bring changes to each surviving members place, role and responsibility within the family unit (Asaro & Clements, 2005). For many families coming to terms with the untimely and unfair nature of the death complicates grief reactions by exacerbating the intensity of feelings of guilt, blame and sometimes revenge, keeping the focus of grief loss orientated and increasing the risk of PTSD (Parkes & Prigerson, 2010; Worden, 2009).

Suicide

Death by suicide also increases the risks of complicated grief and whilst there are similarities to the bereavement experiences of other sudden and traumatic deaths bereavement by suicide is different (Begley & Quayle, 2007; Parkes & Prigerson, 2010; Ward-Ciesielski, et al 2014 Worden, 2009).

Suicide, defined as '*the act of deliberately killing oneself',* is one of the most traumatic and stigmatised modes of death for the bereaved to come to terms with (WHO, 2014:12). The social stigma that continues to surround suicide and mental health means that suicide often remains hidden despite the fact that someone dies from suicide every forty seconds worldwide (WHO, 2014) and every two hours in England and Wales (ONS,2015) making suicide a global public health concern. Global statistics for suicide are 11.4 deaths per 100.000 population 15.0 male and 8.0 females (WHO, 2014). Statistics for the UK show overall figures broadly compare with global suicides 11.9 deaths per 100,000 populations in 2013. The male suicide rate in the UK is slightly higher than global figures at 19.0 deaths per 100,000 but female suicides are lower at 5.1 deaths (ONS, 2015). Overall statistics for suicides in the UK for 2013 recorded 78% male and 22% female suicide deaths. The stark difference and increase in male suicides since 2007 is attributed to the economic recession that began in 2008, whilst female suicide rates have remained stable over this period of time. Suicide is the leading cause of death for males between the ages of twenty and forty-nine and those over seventy-five making male suicide three times as likely as female suicide (ONS2015; HM Government, 2015).

Increased risk factors associated with suicide in men include socio -cultural expectations that men are strong and decisive; this increases pressure at times of stress and increases vulnerability to suicide. Additional risk factors include undiagnosed depression and mental health problems, alcohol or substance misuse, unemployment; relationship problems, divorce and social isolation (Department of Health (DH) 2012; HM Government, 2015).

Bereavement, recognised as one of life's most stressful events is also a significant risk factor in suicide deaths. Bereavement suicide is a particular risk for older widowers perhaps accounting for the higher rates of death by suicide in men over the age of seventy (Worden, 2009; Thompson, 2012; Granek, 2014). Whilst bereavement generally increases the risk of mortality, bereavement by suicide increases the risks and vulnerabilities to death by suicide for the bereaved (Begley & Quayle, 2007). Sugure, McGilloway & Keegan (2014) also noted an increased vulnerability to bereavement suicide attributed to the intensity of the mother child bond in their study of mothers bereaved by suicide.

Suicide is a leading cause of death in England and Wales in 2013, accounting for 24% of all male deaths for men aged between twenty and thirty-four and for 13% of those aged between thirty-five and forty-nine. Similarly for women aged between 20 and 34 years suicide is a leading cause of death accounting for 12% of all deaths, and is the third leading cause of death for those aged 35 to 49 responsible for 6% of all deaths (ONS, 2015:4).

Despite the prevalence of suicide it retains a social stigma differentiating suicide bereavement from other bereavement experiences. A key factor separating suicide deaths from others is that the deceased person made a choice to die. Suicide bereavement is often characterised by a search for meaning, questioning why the deceased took their own life. It is the prolonged search for meaning and fear of recurrent bereavement suicide in other family members that differentiates suicide bereavement from that of other traumatic deaths (Begley & Quayle, 2007). Moreover the bereavement process can be complicated and prolonged by police investigations and an inquest, feelings of rejection or abandonment by the deceased and by social isolation, social stigma and shame that often still surrounds suicide bereavement (Ward-Ciesielski, et al 2014). The stigma attached to suicide is in part due to social awkwardness, perhaps conflicting with religious or spiritual beliefs and lack of understanding of the hopelessness and desperation that makes someone take their own life; this is often aligned to the consideration of suicide as a selfish act. This can make knowing

how to respond to death by suicide challenging for both the bereaved and those around them (Hawton & Simkin, 2008, Dying Matters, 2015).

The global recognition of suicide as a public health issue has seen significant development in support not only for those vulnerable to suicide but also for those bereaved by suicide. As a result of the National Suicide Prevention Strategy the suicide bereavement support partnership was established in 2014 with key national organisations including Childhood Bereavement Network, Child Bereavement UK, Winston's Wish, Cruse and the Samaritans to support those bereaved by suicide (HM Government, 2015).

(Suicide as a prevalent mode of death in Gypsy/Traveller communities is discussed further in part two of this review).

Culture, Trauma and Bereavement

Culture is not just influential in defining the behavioural boundaries for mourning rituals, grief and cultural trauma can impact on individual resilience and coping strategies following a trauma or crisis. Crisis is defined as a point beyond normal range of coping strategies and trauma as a sudden unexpected event that impacts on psychological wellbeing. Furthermore Thompson (2012) defines trauma from three perspectives, firstly, psychologically with impaired cognitive and emotional functioning, with the emotional intensity of trauma similar to grief responses following bereavement. Secondly an individual's reaction to trauma is sociologically influenced by culture, gender and social group behaviours. Thirdly is the spiritual aspect to trauma where religious belief and /or self-belief may be questioned. Therefore whilst bereavement may create both trauma and crisis for an individual cultural trauma or crisis can also extend to whole communities and large scale bereavements. For example cultural trauma is most evident through war, natural disaster, or demonstrated through historic cultural change such as colonialism. Historically cultural trauma has been particularly evident in many indigenous and ethnic minority people (Stamm et al 2003). Cultural trauma impacts on social dynamics, emotions, spirituality and

the resilience of those involved and can have intergenerational impacts on coping mechanisms leading to increased emotional vulnerability (Thompson, 2012).

Resilience to loss

Resilience to loss is increasingly being recognised as a key factor in determining individual responses to grief and the adjustment to loss following bereavement (Niemeyer, 2011, Walsh, 2011). Resilience is a defence mechanism that underpins the ability to overcome psycho-social risk and adversity (Cyrulnik, 2009; Masten, 2014; Rutter, 1981, 1999, 2012; Walsh, 2003). It is the ability to 'bounce back' from stressful and challenging life events and adversities such as poverty, poor health and bereavement by being able to develop and maintain good health and positive life chances (Public Health England, 2014). For example an individual's capacity for resilience is determined by the interplay between family relationships and the environment, with relationships and experiences interwoven over the life course and across generations (Walsh, 2006). Hence resilience is influenced by both family and environmental factors, each of which creates either a positive buffer or increased risk or vulnerability to the development of resilience. Consequently positive relationships and experiences lead to positive outcomes, however when family stability and relationships are debilitated as a result of stressful life events such as poverty, unemployment, poor health or following a family bereavement the outcomes can be very different. Family stress resulting from bereavement can affect the stability and functioning of the family, which in turn has an impact on the resilience of both individual family members and the family unit as a whole (Thompson, 2012).

Having discussed individual resilience the focus now turns to the concept of family resilience and the interdependent relationships between family members that are pivotal to developing and sustaining resilience. Walsh (2011) uses a family resilience framework to identify key aspects of resilience from both an ecological and a family lifecycle perspective. For example from an ecological standpoint socio-cultural risk factors include poverty and discrimination,

whilst positive factors can be found in community and social networks and universal service provision. Whereas the lifecycle perspective considers the family from a developmental stance, assessing how effectively (or not) the family functions and moves forward both within and across generations as a result of family crisis and stressful life events. As with individual resilience family resilience is also based on the balance of risk and protective factors but considers how rather than if a family is resilient (Benzies & Mychasiuk, 2009).

Positive factors can be found in three key domains. The first being family belief systems, families that have shared beliefs and/or that have strong spiritual or religious beliefs are able to provide protective resilience factors. Secondly family structures that are adaptive offering mutual support stability and security facilitate resilience, as do extended family and kinship relationships and social networks. Thirdly good communication and open emotional exchange are also highlighted as positive and protective resilience factors (Walsh, 2011). These protective factors act as a support mechanism or 'buffer' to adversity (Walsh 2003). However individual dispositions for resilience are fluid and changeable over time and in different situations across the lifespan. Moreover individual resilience cannot be considered in isolation as it is influenced by both family and community resilience factors (Reich et al, 2010).

The concepts of community resilience are underpinned by socio- ecological frameworks and consider how communities withstand and develop from adversities linked to environmental change or socio-economic hardship and inequality (Lyon & Parkins, 2013). The similarities in protective and risk factors, albeit in a broader socio-economic context illustrate the interdependence between individuals, family and community structures. These similarities are not surprising given that some community structures, as with Gypsy and Traveller communities, are essentially extended kinship family communities. Hence shared beliefs and values, a sense of belonging and communication are fundamental to both family and community resilience. In addition community trust, social support and social capital (social and economic networks of mutual support) (ONS, 2015), are essential elements in the

development of resilient communities (Kulig et al, 2013). The role that family and community play in supporting health and wellbeing is highlighted in Marmot's (2010) discussion of social capital, where he suggests that close relationships between individuals promotes resilience that can provide barriers to exacerbated health risk.

Thus individual life experiences and how these are managed will determine personal vulnerability to bereavement, with some 'more vulnerable than others' (Parkes, 2011:1). Unlike traditional grief theories which suggested fixed patterns and responses to grief with either excessive or lack of emotional reaction considered pathological, current grief theory recognises individual differences and the impact of resilience on loss and grief responses, advocating that low distress patterns following bereavement suggest resilience to loss. However resilient behaviours do not mean a lack of grief just better adjustment to managing everyday routines (Mancini & Bonanno, 2011). Consequently resilience to loss is demonstrated through the ability to function normally following bereavement, whereas for the majority of bereaved individuals there is some disruption to both physical and psychological functioning. Resilience to loss is characterised and supported by positive resilience factors across other aspects of life. Conversely those who struggle to recover from loss are often less resilient (Mancini & Bonanno, 2011).

Gendered patterns of grief

There is not space in this review to fully explore gender differences therefore a brief summary will consider the impact of gender role socialisation on aspects of life experiences including bereavement.

The discourse surrounding gender is multifaceted encompassing the diversities and socio-cultural behavioural expectations of men and women, including reproduction, power relationships, the division of labour and cultural definitions of masculinity and femininity (Bradley, 2013). Gender is usually defined through the biological differences of being male or female, these differences are often emphasised through socio- cultural patterns of

behaviour. As a result biological differences lead to behavioural differences which are then socially assigned as gendered behaviours (Kimmel, 2000). Thus western socio-cultural structures generally characterise men and women with particular behavioural traits, men are expected to be strong, aggressive and rational with strong sexual desires, whereas women are expected to be intuitive, nurturing, emotional and sexually loyal (Connell, 2009). Consequently biological differences merge with social ascriptions to create gender identities (Mac-an-ghaill & Haywood, 2007).

Additionally the interchangeable terminology of gender and sex that is often used increases the complexity of the subject. Oakley (2005) offers some clarity suggesting that sex is used when discussing the biological differences and the characteristics that define us as male or female, whilst gender refers to psychological influences including the variation of masculine or feminine attributes within differing cultures and the wider socio cultural patterns of behaviour. Therefore Oakley suggests that it is socialisation rather than biological differences that define what is seen as masculine or feminine and subsequently determine gender roles. Jones et al (2011) and Platt (2011) concur that socio cultural values are influential in both structuring and regulating social behaviours and the lived experiences of men and women. In this context gender ascription is a socio-cultural construct in which social systems and values determine the roles and behaviours of men and women. It is within this framework that the following discussion will focus, exploring the impact of bereavement and expression of grief from a gendered perspective.

Defined by socio cultural mores and societal structures gender roles regulate and influence the life chances and experiences of both men and women (Warwick-Booth2013). Throughout history gender role expectations and behaviours have been explicit; men have had dominant roles holding positions of social power resulting in inequality for women, who were considered the weaker sex in need of care and protection by men (Bradley, 1996). Although this power balance has changed within modern western societies there remain significant inequalities between men and women both across and within differing cultures

(Guimond et al 2007). Contemporary western societies have seen rapid generational change in gender role expectations significantly changing the place and status of women from purely domestic roles and being economically dependent on men, to women being economically successful and independent (Giddens, 2013). Moreover the change in status of women has seen a parity of gender roles with both men and women sharing powerful jobs, domestic roles and childcare. However this change is not universal, the position of women in society and global gender role bias remains prevalent in many cultures and societies with inequalities in decision making powers, payment for work, education opportunities and in particular poor maternal health and subsequent child health outcomes still commonplace (Wharton,2005; Commission for Social Determinants of Health (CSHD), 2008).

Given that gender role socialisation is influential across all aspects of life experiences it is not surprising that gendered behavioural patterns are also evident in bereavement behaviours. Cross cultural mourning rituals and grief processes recognise that women cry more than men and that women are most likely to exhibit overt grief and distress whilst men tend to internalise their feelings and are less likely to seek support (Parkes, 2009; Rosenblatt, 2008). These behaviours are governed by the expectations of gender role behaviours often embedded in childhood, such as the expectation that 'boys don't cry'. Moreover the expectation that men will exhibit strength, control and self-reliance creates a conflict between behavioural expectations and the emotions of grief (Parkes & Prigerson, 2010). Gender role socialisation encourages emotions considered masculine such as anger and aggression and not the softer emotions that may suggest vulnerability (such as crying), thus the lack of overt emotional expression can lead to the misconception that men are '*fine'* and not in need of support as they often appear to carry on with life, continuing to work and not demonstrably showing an emotional reaction to grief. However, Doka, (2010:6) suggests that when grieving men refer to themselves as *'fine'*, as is commonplace, it should be viewed as an acronym for *'feelings inside never expressed'* recognising that men do have an emotional response to grief but it is not obviously evident or expressed and may be

conveyed according to gendered behavioural expectations rather than the societal behavioural norm which favours an affective approach to the expression of grief.

The current Western societal approach to the support and management of grief through the expression of emotion and counselling has a feminine affective approach which Doka & Martin (2010) argue is more suited to the bereavement behaviours of women than men, hence why men are often viewed as either not grieving or as ineffectual grievers. Furthermore Doka & Martin (2010) provide some insight into the differing patterns of grief between men and women, proposing that generally women are intuitive grievers, an affective model of emotionally focused responses, whereas men are more likely to follow an instrumental pattern of grief which has a cognitive or problem solving approach expressed through physical activity and behaviours. Although instrumental patterns of grief are commonly associated with the way men grieve some women will also favour this approach. Therefore intuitive and instrumental patterns of grief are best viewed as a continuum rather than definitive styles and whilst the majority of men will exhibit instrumental patterns and most women intuitive, individual experiences, cultural and gender role socialisation will affect where on the continuum between intuitive and instrumental individual responses to grief are situated. Patterns of grief are also influential in the way society responds to different types of loss, characterizing in gendered behavioural expectations which reinforce intuitive and instrumental patterns of grief as gendered behaviours. These are evident when considering significant losses such as the loss of a spouse or child (Doka & Martin, 2010).

Gendered differentiated grief patterns following Spousal loss

There are a number of influential research studies on spousal loss most notable are those of Bowlby (1981), Parkes (1972) and more recently Stroebe and Stroebe (2001) and Bennett et al (2003), all of whom have considered gender differences in the bereavement patterns of widows and widowers. The patterns of grief and behaviours attributed to widowers include an earlier social recovery than widows, returning to work soon after loss with work used as a

distraction from grief. Men are also more likely to remarry than women (Stroebe, et al, 2001; Bandini & Thompson, 2013). This is in part due to the need to provide family stability for younger widowers with children and for older men is often related to the higher mortality rates of men meaning that widows outnumber widowers.

Moreover being widowed impacts of the social role and masculine identity as a married man, so remarrying is also about regaining social roles and status (Bandini & Thompson, 2013). Widowers also exhibited less obvious emotional responses than widows and were found to be less likely to seek external support. However although men are less likely to seek support for themselves they were still expected to be strong and supportive of others, thus reinforcing stereotypical gender role behaviours and instrumental patterns of grief. As a result the health and wellbeing of widowers may be overlooked with the presumption they are coping with their loss, when in fact the opposite is more likely, as exemplified through Stroebe and Stroebe's (2001:78) conclusions that '*widowers suffer more than widows'*. The rationale for this statement suggests that although generally widows show more immediate and overt emotional distress and may experience depression within the first year following the loss of a spouse; widowers are more likely to die within the first year and to be suffering from depression two to four years after the loss and using alcohol and other substance misuse as coping strategies (Fried et al, 2015; Van-der-Houwen et al, 2010). Therefore whilst the gender role expectations and coping strategies used by widowers appear to be detrimental to the recovery from spousal loss, the patterns of grief of women through the overt expression and seeking and use of social support mechanisms, including counselling appear to be more beneficial to the management and recovery from grief and loss of a spouse than the often misinterpreted instrumental approaches of men (Doka & Martin, 2010; Parkes & Prigerson, 2010). Thus the complication of applying gender role expectations and behaviours to patterns of grief means that the grief of men is not always recognised as such. The instrumental pattern of grief favoured by the majority of men which perhaps gives the outward appearance '*just carrying on with life'* results in the application of gender role

expectations that men are strong and able to cope and not in need of support often failing to acknowledge their grief. Moreover the gender role orientation towards patterns of grief, and the stereotypical societal interpretation, recognising grief of women but not always acknowledging grief in men is particularly evident when considering the role of men as fathers following the loss of a child (Murphy, 2013; Niemeyer et al, 2014; Stroebe et al, 2013).

Gendered differentiated grief patterns following the loss of a child

The loss of a child remains one of western society's taboo deaths, childhood mortality rates are decreasing year on year (with infant mortality at 3.9 per thousand live births in England and Wales in 2014 (ONS, 2014) and although there are exceptions in some ethnic minority groups including Gypsies and Travellers where infant and child mortality remains higher than the norm, children are expected to live not die (Reid, 2005; Matthews, 2008). Today there is an increasing recognition of prenatal loss as bereavement and the importance of providing support for parents (Stroebe, Schut & Finkenaur, 2013). In the past infant death particularly miscarriage and stillbirth have been stigmatised deaths, with parents feeling they have failed in their social roles, not becoming parents of the healthy child that they expected to be, thus they are bereaved of both their child and of the social role of being a parent (Murphy, 2012). As a result pregnancy losses often remain socially unacknowledged and parental grief silent and internalised. Moreover prenatal losses have been devalued as bereavements; with early pregnancy miscarriages not recognised as viable life, so not acknowledged as deaths, whereas a stillbirth is a recognised death but the baby's body has historically been quickly removed often without parents having the chance to see or hold their baby (Lovell 1997). The removal of the baby was linked to the perception parents would not grieve if they did not see the baby (Koopmans et al, 2013). The recognition of pre-natal attachment bonds has seen current practice much improved, with the acknowledgement that strong attachment bonds are formed as the baby develops within the womb and that although the intensity of these bonds will be greater for the mother, fathers also have a prenatal attachment to their

baby (Vreeswijk et al, 2014). Therefore to support their grief bereaved parents need to be able to say goodbye to their baby and to be able to mourn. An important aspect of this is for the baby to be socially recognised, to be named and buried thus giving parents a physical representation of their loss. Whilst this is possible with stillborn babies it is not with miscarriages meaning that they often remain a hidden or disenfranchised loss mourned only by the parents and not openly acknowledged by wider family and society (Bowlby, 1981; Doka & Martin, 2010; Raphael, 1984).

Parkes and Prigerson (2010:147) suggest that following the loss of a child '*mothers and fathers grieve differently; mothers grieve for their baby fathers grieve for their wives'*. Given that this discussion has earlier identified the differences and influences of gender role socialisation in how men and women grieve it is not surprising that as the above quote suggests maternal and paternal grief will differ, what it does not do is recognise that fathers also grieve intensely for the loss of their child.

Following the loss of a baby or child the focus of support from medical practitioners tends to be on the mother recognising her loss but not that of the father, particularly in a prenatal loss paternal grief is often not acknowledged following assumptions that male attachment develops after birth, despite evidence to the contrary that fathers also experience intense grief following the loss of a child (Koopmans et al, 2014; Stroebe, Schut & Finkenaur, 2013). However social roles expect that men will be strong and provide emotional support for their wives or partners without consideration that they may also be grieving. In conforming to gender role stereotypes paternal grief, often expressed through anger and aggression as a protective strategy towards supporting their partner means that the fathers' grief can remain hidden and unacknowledged (Aho, 2011; McCrieght, 2004). Paternal grief is therefore constrained by gender role expectations creating juxtaposition between social and personal expressions of grief (Worden, 2009).

Once again gender role socialisation and instrumental patterns of grief appear detrimental to both the recognition and resolution of grief for men. Furthermore the differences in patterns of grief can create relationship problems for the bereaved parents as they are unable to understand and support each other's differing responses to grief. Maternal grief is usually prolonged and often results in depression and social withdrawal whilst paternal grief outwardly appears less intense with a faster recovery time (Aho, 2011).

Despite the fact that gender role socialisation often appears to favour men, when it comes to grief and loss women appear to fare better than men as current models of support are orientated towards intuitive grief patterns and overt expression of emotion. This approach pathologises instrumental and masculine responses to grief leading to the assumption that a lack of emotional expression means that men do not grieve, or are ineffective grievers when in fact they just grieve differently. Therefore whilst gender is important individual patterns of grief are '*influenced by but not determined by gender'* (Doka & Martin, 2010:4).

Culture and gender are both significantly influential factors in determining expected societal patterns of behaviour, these alongside personal factors such as resilience, health and wellbeing will impact on individual responses to grief.

Thus far the focus of discussion has been on adult responses the grief, however, it is also important to consider the impact of bereavement on children and their grief responses as many of the problems experienced by adults, particularly mental health and wellbeing often have their roots in childhood experiences. Consequently early childhood experiences are pivotal to outcomes and life chances as adults (Field, 2010; Allen, 2011; Lemer, 2013).

Children and bereavement

Historically children would have experienced death as part of everyday life; children were viewed as small adults and fully involved in all aspects of adult life. Witnessing death at home would have been commonplace (Cunningham 2006). However childhood in the twenty first century Western society is very different, childhood is recognised as a distinct life stage with children as the focus of the family, where they are nurtured and protected (Wells, 2009). Children today are often excluded from death and death rituals through the belief that they are too young to understand or that they should be protected from the grief and loss (Cranwell, 2007). However death remains as central to society today as it was historically, and whilst parents may wish to protect children, the media exposes children to death from homicide, war and natural disasters (Ribbens-McCarthy, 2006; Draper & Hancock, 2011). This death at a distance is obviously less meaningful than the loss of a family member, yet provides the opportunity for children to develop an understanding of mortality and loss (Way, 2013). Similarly pet loss or loss of friends and family due to geographic moves can offer some preparation for loss (Corr & Balk 2010).

To be able to understand and provide effective support for children it is essential to appreciate and value their understanding of the concepts of death. Silverman (2000) provides an overview of a developmental approach to children understanding death, suggesting that children do not understand the finality of death until the age of five years old. Furthermore Silverman (2000) proposes children who have experienced bereavement have a different level of understanding than non-bereaved children, one that is much more emotional and irrational than just a linear cognitive approach that is linked to age. This view supports Piaget's (1969) empirical developmental view of learning and understanding gained through the assimilation of experience. Consequently children who have experienced bereavement will have a very different viewpoint and understanding of death than those without such experience.

Piaget's stage based theory is based on the premise that children move through the stages from ego-centric thinking to abstract conceptual thought processes. Piaget claimed that children develop their knowledge by making meaning of, and learning from their experiences. This is achieved through the development of schemas, or mental representations of the world. Schemas change as the child develops and the breadth of knowledge and experiences grows. New knowledge and information is assimilated, fitted into an existing schema to make sense of the experience or *accommodated.* Accommodation is the process of developing *a* new schema when the new knowledge or information does not fit an existing schema. For Piaget this developmental process is stage based and age related. The stages start with the sensory- motor stage from birth to two years old where learning is primarily gained through sensory and physical interaction. This is followed by the pre-operational stage between the ages of two and six years old when the child's world view is predominantly ego-centric thinking. Stage three, concrete operational thinking occurs between the ages of six and twelve years old. As the child matures thought processes become logical but remain focused on concrete objects and experiences. In the final stage, formal operations abstract thought is achieved (Piaget, 1969).

Kane's (1979) study on how children understand the concepts of death is also stage based and aligned with Piaget's stages of development. Kane developed a three stage model and a series of concepts that illustrate children's developing understanding of death. These concepts include:

Realisation: awareness of death as a life event.

Separation: understanding that the dead are located in a separate place.

Immobility: understanding that the dead no longer move.

Irrevocability: acceptance of the permanence of death.

Causality: understanding the cause of death.

Dysfunctionality: understanding that the body no longer works.

Universality: recognition that death happens to everyone including self.

Insensitivity: understanding that the dead no longer think or feel.

*Acceptance**:*** recognition that the dead look different to the living**.**

Kane (1979) suggests that at stage one children's understanding of death is structural and aligned with Piaget's pre-operational stage of development. Children's thinking is egocentric; they think they can affect death and will often feel guilt or blame themselves for the death. Representation of death is descriptive and physical and includes some understanding of the concepts of separation and immobility. Stage two, linked to Piaget's concrete operational stage demonstrates functional thinking and concrete representation of the dead, children's patterns of thinking develop throughout this stage moving from concrete thoughts, such as the dead cannot move or eat, towards more abstract concepts and understanding of death. The concepts of irrevocability and causality and dysfunction will begin to be understood. In stage three abstract thought is achieved with the concepts of realisation and universality recognising death as a universal life event. Throughout all of the stages the understanding of each concept will increase in line with the development and maturity of each child. As the cognitive understanding of children develops so their understanding of death changes therefore bereavement and grief becomes an evolving and continual process throughout childhood and adolescence as children will revisit and re-experience their grief as they progress through each developmental stage (Biank & Werner-Lin, 2011; Christ,2000; Mallon,2011).

Short term responses to bereavement

Children's responses to grief, just like those of adults, will be individual determined by their age and stage of development as well as family circumstances and the availability and quality of support they receive (Dyregrov & Dyregrov,2013).

Young children may not show any reaction when told of a death; they will understand that a key person in their life is missing particularly if it is a parent and main attachment figure. For very young children the most obvious indicator of loss will be exhibited through separation anxiety (Bowlby, 1980; Kubler-Ross, 2008). Loss for babies and children under the age of two impacts mostly on the development of attachment, up to this age infants are developing mental representations, of their primary carer giver (usually the mother), these become *'hidden regulators'* that are established through the sensory representations and routines that develop the behavioural patterns create attachments to the primary carer. Loss of this person can result in poor self-regulation, erratic emotional responses and difficulties developing attachment relationships (Di Ciarro, 2008; Moullins, et al, 2014).

Preschool children may not be able to verbalise how they feel however, may exhibit physical and behavioural symptoms such as loss of appetite, insomnia, regressive behaviours. Children at this age use symbolic play to represent their world view acting out the thoughts and feelings that they may not be able to understand and verbalise (Bugge, 2014). This can include '*magical thinking'* whereby the child believes he or she may be responsible for the death, but may be able to reverse death by carrying out particular actions or behaviours. It is not until around the age of five that children understand the universality of death, which can create fear that they or other family members will also die (Mallon, 2011).

By middle childhood, around the age of eight children are developing an understanding of cause and effect so have a better contextual understanding of death and loss, however this can lead to an irrational sense of guilt or blaming themselves for the death of their loved one

as they struggle to come to terms with their loss (Di-Caricco, 2008). Worden (2009) suggests children at this stage of development are particularly vulnerable as they have conceptual understanding of the permanence of death but may not have the socio-emotional coping skills to manage their grief.

Bereavement for adolescents brings additional challenges, although they may have a better conceptual understanding of death and loss the increased awareness of their own mortality often leads to an escalation in risk taking behaviours (Ribbens-McCarthy & Jessop, 2005). As they struggle with the transition from child to adult, they may find it hard to ask for support and may challenge cultural or family beliefs as they develop their own strong views and opinions and strive for independence (Ribbens-McCarthy 2006). Adolescence is a time of transition and intense emotional response which following bereavement can lead to either withdrawal and isolation or increased risk taking behaviours. Eating disorders and suicide ideology can be a concern at this age (Mallon, 2011).

Childhood and adolescence are significant times of change and development, normative transitions, from early childhood transitions from home to school to transitions and to adolescence and adulthood create emotional instability, but unexpected transitions such as bereavement fundamentally change the life world often through changes in family structure and functioning, creating *'emotional chaos'* (Ribbens- McCarthy,2006). Children's reaction to bereavement and grief is influenced by attachment relationships and emotional resilience, both of which are developed from positive parental interactions, conversely children who have insecure attachments are more likely to be less resilient to change (Moullins et al, 2014). Stoke's (2009) study of resilience and bereaved children found that approximately 10% of children, those with the most supportive and stable family networks showed high levels of resilience following parental loss, the majority, 75% of children had moderate levels of resilience with 15% of children, namely those who lacked parental support or who were in social care were considered highly vulnerable with low resilience and in need of professional support.

Supporting bereaved children

Support for children following bereavement comes primarily from family; and whilst this will be sufficient for many children for some the emotional complexities of family relationships following bereavement mean that children do not always have the opportunity to talk about the deceased (Fauth et al, 2009). Despite growing recognition that children do grieve and that bereavement can have long term effects of their health and wellbeing both in childhood but also as adults children's needs following bereavement often remain overlooked (Lemer, 2013, Akerman & Statham, 2014).

Dyregrov (1996) reiterates the importance of the inclusion of children in death rituals; he discusses the developmental advantages but also importantly recognises the right of the child to be included. Dyregrov suggests that death rituals are an important part of the grief process for adults and children, a time to say goodbye and make sense of and accept the reality of the loss. This is particularly important for children as rituals provide a physical representation aiding their developmental understanding of what has happened. Moreover Dyregrov (1996) cautions that denying children the opportunity to participate in rituals excludes them from an important family occasion that can have long term implications for their grief reactions. Children given the opportunity to experience grief as an early life experience have the capacity to cope with grief and loss developing emotional strength and resilience if well supported (Dyregrov, 1991). Rutter (1981) concurs stating that *'preventing children from experiencing major life events will leave them ill-equipped to deal with life.'* Providing children are well prepared and informed about what will happen or what they will see and are well supported children will develop resilience and emotional coping strategies that will help to prepare them for later life experiences. Whilst hearing the voice of the child is important when considering attendance at death rituals it is also fundamental to the ongoing bereavement support needs of children.

In Silverman and Worden's (1992) study of parentally bereaved children, which remains one of the most influential studies of childhood bereavement, children highlighted their support needs as:

- Needing information about what has happened.
- To be listened to and reassured about their fears and anxieties,
- Reassurance they are not to blame,
- Inclusion and involvement in discussions and rituals,
- To have opportunities to remember and talk about the deceased person (Worden, 2009).

All of these are vital to enabling children to make sense of their loss and to adjust attachment relationships and redefine continued bonds with the deceased. Findings from the Childhood Bereavement Network campaign Grief Matters, reiterates the importance of being listened to and being able to talk about the deceased as fundamental aspects of their responses to grief and loss (Penny, 2007).

However, particularly for children bereaved of a parent or sibling family support is not always sufficient. One of the challenges for supporting bereaved children is that parents, who are often also grieving, do not always understand their children's needs or behavioural changes following bereavement, making it difficult for them to offer support (Bugge, 2014). Ribbens-McCarthy & Jessop (2005) found that many adolescents had not discussed their bereavement experiences with anyone and approximately one third of bereaved children seek external support (Fauth et al 2009).

Schools have a pivotal position in providing bereavement support for children and an educational awareness of death and loss as a normative life process. In particular the personal, social and health education (PSHE) aspects of the curriculum offer opportunities for children to gain understanding of death and loss, grief and bereavement through health education, emotional literacy and the development of resilience (Job & Frances,2004).

However cross curricula opportunities can also be effective, discussing lifecycles and pet loss or through literacy as many children's stories, such as Harry Potter portray the lives of children following the death of their parents. Sensitive use of such stories can offer the opportunities to discuss feelings and emotions relating to loss. In addition schools can offer strong pastoral support and often be a place of stability and security for bereaved children when many other aspects of their lives change following a death in the family (Mallon, 2011; Weymont & Rae 2006).

Akerman & Statham (2014) conclude that many children and their parents' access support services to aid family communication and to find peer support and understanding following the death of a significant person in their lives. Children's bereavement support needs, just as those of adults are individual and support provision needs to be tailored to meet the needs of the individual rather than universal service provision. Similarly to the recommended support services for adults Akerman & Statham (2014) cite a tiered model of support as good practice in providing individually differentiated support. This includes generically accessible information about how children grieve through to more targeted peer and family support and specialist services for vulnerable or traumatised children. The recommendation of similar service provision for both adults and children highlights the need to acknowledge and support grieving children, recognising that children experience grief as adults do (Weymont & Rae 2006).

Acknowledging the similarities between adult and children's grief raises questions about how theories and models of grief apply to children. Worden (2009) cautions that whilst the tasks of mourning will apply to children just as they do adults, some adaptation is necessary for children taking their age and stage of emotional and cognitive development into consideration. For example task one acceptance of loss cannot take place until the cognitive ability to understand the finality of death is achieved at approximately five years of age.

Stroebe and Schut's (1999) dual process model provides a good representation of children's grief as they alternate between grief and loss orientated behaviours and normative routines and adaption to change in restoration orientated behaviours. Children dip in and out of grief as a stress management technique and as their development progresses.

The continuing bonds model, developed from the Harvard Child Bereavement Study highlighted the strong connections maintained with the deceased over time (Klass, Silverman & Nickman, 1996; Worden & Silverman, 1992 cited Worden, 2009). This model reflects the reality that grief is not resolved but involves the integration of the deceased into the adapted life world of the bereaved. For children shared memories, photographs and stories help to adapt and maintain continuing bonds with the deceased. The use of stories and memories are helpful in a number of ways, maintaining a bond and memory of the deceased but also as a therapeutic tool to help children express their feelings and support their developmental understanding of bereavement and loss helping them to work through the process of grief (Mallon, 2011).

To conclude this section of the literature review it is important to remember the individuality of bereavement experiences for both children and adults. Whilst bereavement is a normal life process that affects us all, individual life experiences and socio cultural mores will influence patterns of grief and mourning.

The focus of the review will now consider the culture, life styles and experiences of Gypsies and Travellers. As the most marginalised ethnic group in the UK (CRE,2006) Gypsies and Travellers often live in high states of crisis and trauma, particularly those who remain nomadic, with frequent evictions and high incidences of sudden or traumatic death they are particularly vulnerability to poor health and high mortality rates (Cemlyn et al, 2009).

Part 2: Gypsies and Travellers

Gypsies and Travellers who are they?

Despite various estimates the size of the Gypsy Traveller population remains unclear. In 2006 the Commission for Racial Equality (CRE) suggested that there may be as many as 300,000 Gypsies, and Travellers in the UK. However the 2011 Census identified much smaller numbers, 58,000 (ONS, 2014). Following this disparity the Traveller Movement in Britain sought to find a more accurate account using population data from Gypsy Traveller Accommodation Needs Assessments for 2011, these identified the population as 119,193 more than double the numbers suggested by the census (ITMB, 2013). Acton et al, (2016) suggest a best estimate of no less than 125,000 and no more than 250,000 Gypsies and Travellers residing in the UK. This is surmised from considering inconsistencies in categories used and data collection methods from census data and local authority Gypsy and Traveller accommodation needs assessments (GTAA). Acton et al (2016) suggest that differentiated categories are perhaps used for political policy gain, for example, undercounting through lack of ascription in GTAA data can suit policy agendas as inaccurate numbers may imply a reduced need for legal site provision for those choosing to live in trailers. These anomalies suggest and inconsistent approach to how Gypsies and Travellers ascribe themselves, only sometimes and in some circumstances do they offer their true ascription as a Gypsy or Traveller.

This disparity highlights the invisibility of Gypsies and Travellers as they remain a largely hidden community in mainstream consciousness. In part this invisibility is used as a protective strategy by the community, to maintain their distinct culture and heritage and prevent assimilation into the sedentary society (Liegeois, 2007; Powell, 2008, 2013). However, invisibility also keeps them marginalised and misunderstood by the wider population creating a dichotomy of views, from the historic and romanticised notion of a nomadic lifestyle with horse drawn wagons in country lanes juxtaposed against the more

recent stereotypical view of ‘dirty’ and ‘dishonest’ people living in illegally parked caravans (Evans,1999; Richardson et al, 2007). The reality is in fact, a marginalised community who have experienced a long history of prejudice and discrimination dating back to the sixteenth century.

Although it is widely recognised that Gypsies and Travellers have been present within British society since the sixteenth century, the origins of this ethnic group are unclear (Bancroft, 2005). Historic evidence provides a number of hypotheses which are predominantly based in myth and folklore due to the oral and illiterate heritage of Gypsies and Travellers. Despite a lack of quantifiable evidence of origin, the most compelling evidence suggests Gypsies originated from India. This hypothesis was developed from nineteenth century linguistic studies, based on similarities between Romany and Indic Hindi and Sanskrit languages (Okely1983).

The romanticised notion of exotic Travellers, common to first sightings of this population (Evans 1999) did not last long as the numbers of travelling people increased and legislation discriminating against travelling people emerged. Thus legislation as early as 1530 saw a change in the perception of Gypsies from exotic dancers and fortune tellers to rogues and vagabonds who were aligned with vagrants and other travelling or displaced groups of people. This early legislation discriminated against the individual, firstly against those calling themselves ‘Egyptians; and later extended to include vagrants and vagabonds as the numbers of wandering and displaced persons increased. (Liegeois 2005; Okely1983; Taylor, 2014). By the seventeenth century Irish Travellers had arrived in mainland Britain working as itinerant pot-menders and the increasing number of nomadic travellers led to a shift in the focus of legislation from the characteristics of the individual to the use of roadside stopping places. The increasing dichotomy between travelling and sedentary lifestyles resulted in the Turnpike Act in 1822 and later the 1835 Highways Act (Clark & Greenfields 2006) which fined Gypsies for stopping at the roadside. This legislation laid the foundations for further limitations which increasingly restricted the roadside stopping places available to Gypsies

and Travellers with the outcome that today an estimated two-thirds of the Gypsy and Traveller population now reside in housing (Cemlyn et al 2009; Greenfields & Smith, 2010).

Liegeois (2005) asserts that the folklore surrounding the origins of Gypsies and Travellers results from stories they have used to protect themselves and their distinct cultural identity to prevent assimilation into the sedentary society by being 'settled'. History demonstrates that it is the itinerant aspect of Gypsy and Traveller lifestyle that the sedentary population find most challenging with the need to identify a place of origin linked to being settled in one place (Okely1983; Powell, 2008). Whilst the origin of Gypsies and Travellers remains unclear there is no doubt that throughout history as today, they continue to face persecution and discrimination (Taylor, 2014).

In order to explore the situation of the communities being researched it is necessary to identify subjects of the study. Today Gypsy and Traveller is the generic term used to identify nomadic groups. These include English Romany Gypsies, Welsh Gypsies, Scottish and Irish Travellers, Show people (Fairground Travellers), Bargees (barge or boat dwellers), and New Travellers (Clark & Greenfields 2006). It is noteworthy that not all groups receive the same legal recognition and protection, Romany Gypsies, Irish Travellers and Scottish Travellers are recognised as ethnic groups under the Equality Act 2010. Despite this legislation there is little research or national data for this community, as historically they have not been given a distinct ethnic identity in national statistical data collection. Where ascription information is available, through school data collection, it suggests that Gypsies and Travellers will often conceal their true ethnicity for fear of prejudice and discrimination and social exclusion (DCSF, 2009; Ryder, Cemlyn & Acton, 2014). This trend is evident in the Census data for 2011 where for the first time separate ethnic coding for Gypsies and Travellers was included. The results of the Census highlight that identifying '*true'* ascription remains an issue, with only 58,000 or 0.1% of the population identifying themselves as Gypsies and Travellers (ONS 2011). Despite the fact that the census does only identify population figures for England and Wales, there is a significant shortfall in contrast to the estimated numbers of

300,000 across the UK. Furthermore whilst fear of prejudice is a barrier to self-ascription low literacy levels and educational attainment are also influencing factors creating barriers to social inclusion (ITMB 2013). Finally whilst legislation should provide protection and equality for Gypsies and Travellers they remain some of the '*most vulnerable and marginalised ethnic groups'* (Commission for Racial Equality (CRE) 2004).

It is well attested that Gypsies and Travellers face increasing challenges to their culture and traditional nomadic lifestyle (Cemlyn et al, 2009; Quarmby, 2013; Ryder, Cemlyn & Acton, 2014). For example, research highlighting the inequality and marginalised lifestyle experienced by Gypsies and Travellers suggests that legislation and policy continue to discriminate against them, preventing rather than protecting the traditional nomadic lifestyle favoured by these communities. This is nothing new in Western Europe as evidenced by the following statement.

> *'For both social and economic reasons it is clearly undesirable that a section of the population should be isolated and follow a way of life which is harsh, primitive and of low economic value both to those who follow it and to the nation and, most important, which tends to create a closed and separate community which will become increasingly inferior to the rest of the national population and from which it will become increasingly difficult to escape.' (Commission on Itinerancy, 1963:104).*

It is arguable that little has changed since this statement from the Irish Commission on Itinerancy in 1963. Whilst on the surface it might appear supportive; aiming to improve the lifestyles of marginalised groups, it could also be perceived as a prejudiced statement seeking to neither value nor respect the traditional lifestyle of Gypsies and Travellers, in fact condemning them to the conformity of a settled lifestyle which has not proved unproblematic (Greenfields & Smith, 2010). Looking forward to the twenty first century little has changed as legislation and policy continues to work against rather than in favour of Gypsy and Traveller communities (Ryder et al, 2011). It is arguable that the point of view of the dominant society has struggled to take precedence over the lifestyle choices of the minority. The Commission on itinerancy proposed that a nomadic lifestyle is detrimental to Gypsies and Travellers. To some extent this is true; given that increasingly policy prevents the

continuation of a travelling lifestyle as they are progressively becoming a more settled population who continue to live separate but parallel lives with sedentary society (Commission for Racial Equality (CRE), 2006, Powell, 2008; Greenfields & Smith, 2010).

The separateness of Gypsies and Travellers contributes to the limitations of statistical research data available, as prior to the 2011 Census Gypsies and Travellers have not been included or identifiable in administrative data collection. Consequently in terms of hard data they remain a marginalised and isolated community (CRE, 2006). Despite their recent inclusion in Census the evidence remains limited with Census data identifying only 58,000 or 0.1% of the population as Gypsies and Travellers (Office of National Statistics (ONS), 2012). However it is believed that the population is significantly larger, approximately 300,000 as stated earlier (CRE 2006). This demonstrates the continuing trend within the Gypsy and Traveller community of hiding their true ascription for fear of prejudice and discrimination which continues to make it difficult to inform policy and practice which meets the needs of this ethnic group. (Wilkin et al, 2009) However there are an increasing number of research studies and reports looking at all aspects of Gypsy and Traveller lifestyles, including accommodation, health, economic and equality issues. Whilst these research reports predominantly have specific and different focuses there are a number of key themes arising from all of them. One of the most prevalent is the discrimination that Gypsies and Travellers face associated with their lifestyle, choices. This is a significant factor influencing premature death (Clark & Greenfields, 2006, Van Cleemput, 2000). The mortality rate is significantly higher in Gypsy and Traveller communities than the sedentary population, with life expectancy reported to be twelve years less for women and ten years less for men than the general population (Parry et al, 2004).

Therefore bereavement is a significant health concern for Gypsies and Travellers and is often the underlying or unrecognised factor causing increased health problems, such as stress, anxiety and risk taking behaviours. Parry et al (2004: 51) describe bereavement as a '*precipitating factor'* in the use of harmful health behaviours including smoking, drug and

alcohol misuse. It is arguable that the increased use of alcohol and self-medication are used as coping strategies in the absence of formal or specialist bereavement support (Richardson, 2007; Cemlyn et al, 2009).

Parry et al's (2004) Department of Health commissioned report remains the most influential study of Gypsy and Traveller health. The findings of significantly greater health inequalities for these people than are found in the sedentary population are pertinent to this study as the increased health problems are juxtaposed against the increased mortality rates found in the Gypsy and Traveller communities demonstrating the disproportional prevalence of bereavement within Gypsy and Traveller communities compared to the sedentary population.

The separateness and lifestyle choice, which is favoured by many Gypsies and Travellers which is at odds with mainstream society (Liégeois, 2007) has resulted in a complex and difficult relationship between Gypsies, Travellers and the state (Bancroft, 2005; CRE, 2006). Consequently both social and economic exclusion (Ryder & Greenfields, 2010) has led to Gypsies and Travellers having the poorest life chances of any ethnic group in the UK (Diacon, 2007). This high level of exclusion is particularly evident when considering the poor health status and rates of premature mortality within Gypsy and Traveller communities (Parry et al, 2004) in comparison to the mainstream population. It is the socio- cultural significance of bereavement and impact of grief that is the focus of this research and just as it is essential to understand the differences in lifestyles and life chances of Gypsies and Travellers and mainstream society, it is equally important to understand the cultural attitudes and behaviours relating to death.

Why are Gypsies & Travellers vulnerable?

The marginal place of Gypsies and Travellers, living on the edge of mainstream society increases their vulnerability across all aspects of life, for example, increased accommodation, heath, education and employment risks (Greenfields, 2012). The following sections highlight the inequalities faced by Gypsies and Travellers living in twenty-first century Britain and explore the relationship to health status and premature mortality.

Accommodation

Article eight of the European Convention on Human Rights (ECHR) (1953) promotes the '*respect for* an *individual's private and family life, home and traditional way of life',* something that most of the mainstream population would take for granted. However for Gypsies and Travellers prejudices, discrimination and policy development which emphasises sedentary lifestyles typically does the opposite failing to respect the right of Gypsies and Travellers to a follow traditional nomadic lifestyle should they choose to do so. Theoretically article eight places a duty on local authorities to respect this lifestyle choice of Gypsies and Travellers but an increasing loss of stopping places, means that Gypsies and Travellers are in practice having to adopt a settled lifestyle or live in inadequate environments and roadside encampments (Richardson et al, 2007; Ryder & Greenfields, 2010; Department for Communities and Local Government, 2012) Currently as many as two thirds of Gypsy/ Travellers have moved into '*bricks and mortar'* housing, for some, particularly those with poor health moving into housing eases access to health service provision. However, for as many as 40% of families it is less of a choice but as a result of a lack of permanent and legal stopping places (Greenfields & Smith, 2010; Smith & Greenfields, 2015). Moreover the cultural aversion to living in bricks and mortar and the associated risks to health and wellbeing experienced by some Gypsies and Travellers, have been recognised in law through the Human Rights Act (Greenfields & Smith, 2010a).

Cemlyn et al (2009) suggest that accommodation is pivotal to many of the issues faced by Gypsies and Travellers today. One in four Gypsy and Traveller families are living illegally and in poverty on inadequate sites or road side stopping places which are often unhygienic with poor or no sanitation facilities and a lack of safe outdoor play space for children (Greenfields, 2006; Cemlyn et al, 2009). The consequences of this, often enforced change of lifestyle, and the prejudice and discrimination Gypsies and Travellers experience throughout their lifetime frequently has a significant effect on health and wellbeing. Van Cleemput (2000) states that the poor health outcomes experienced by Gypsies and Travellers are not specifically related to the mobility of their lifestyle, but that the anxieties and pressures caused in trying to maintain their traditional lifestyle in the face of a hostile policy environment is a factor causing poor health, perhaps contributing to the high suicide rate within Gypsy and Traveller communities. Therefore accommodation appears to be the catalyst for the plethora of inequalities and problems experienced by Gypsies and Travellers today, underpinning the difficulties faced in relation to accessing health, education and employment (Diacon, 2007; Richardson & Smith-Bendell,2012).

Education

'Education shall aim at developing the child's personality, talents and mental and physical abilities to the fullest extent. Education shall prepare the child for an active adult life in a free society and foster respect for the child's parents, his or her own cultural identity, language and values, and for the cultural background and values of others.' (UNICEF 1989)

Article twenty-nine (above) of the United Nations Convention on the Rights of the Child states that the aim of education is to encourage the child's potential, prepare them for adult life and promote cultural identity and values. Considering education under these terms means that as in many other areas of their lives Gypsy and Traveller beliefs and traditions are at odds with the mainstream provision. For example historically education for Gypsies and Travellers has been focused on life skill development and learning related to

employment and gender role expectations, with girls expected to carry out domestic tasks and boys learning the family business from working with their fathers rather than formal state education.(Clark & Greenfields, 2006; Powell, 2011). However, in recent years there is a notable change in parental attitudes to formal education with a recognition that children will need to be literate to survive economically as a result of the changing twenty- first century economy and increasing loss of traditional Traveller occupations such as gardening, agricultural and scrap metal work (Ryder & Greenfields, 2010).

Despite this the educational attainment of Gypsies and Travellers remains low for the following reasons, poor school attendance, sometimes due to mobility, or as a result of bullying, or poor parental literacy making it difficult to engage with the formalities of schools. In addition gender role expectations and early transition to adulthood with boys working in the family business and girls removed from secondary schools, (particularly mixed schools) to protect their sexual reputations and prevent associations with non-Gypsy boys, means that the majority of Gypsy and Traveller children leave formal education at the end of the primary education phase (Communities & Local Government 2012). As a result the gap in achievement compared to the sedentary population continues to be a concern, with only 25% of Gypsy and Traveller children achieving national expectations at primary phase in comparison to 74% of children from the mainstream population and only 12% of Gypsy and Traveller children achieving five or more GCSEs. (Wilkin et al 2009). This lack of functional literacy within the majority of Gypsy and Traveller communities is a significant factor contributing to their disempowerment and lack of access to mainstream services including health care (Ryder 2012). Low literacy attainment has resulted in a community that is less aware of health promotion and still reliant on oral traditions of passing information from generation to generation. Health information is often based on old traditions and therefore may be inaccurate and outdated leading to preventable deaths. Parry et al(2004) cite educational disadvantage as the most significant difference in the access to health services between Gypsies and Travellers and other ethnic minority groups.

Gypsy and Traveller Health

The health of Gypsies and Travellers is '*significantly poorer'* (Parry et al, 2004:1) than that of comparative ethnic minorities and economically disadvantaged groups. Parry et al's (2004) study remains the most influential health report relating to Gypsies and Travellers to date with findings suggesting that the health problems of the Gypsy and Traveller community are two to five times greater than found within the majority population. The increased health problems are attributed to a lack of access to and trust in health services based on experiences of prejudice, discrimination and the difficulties associated with frequent evictions and the mobility of the community (Hodgins et al, 2006, Aspinall, 2014). In addition a study comparing health and the use of health services of Gypsies and Travellers with Afro Caribbean, Pakistani and white low income groups found that there were significant health inequalities for Gypsies and Travellers in comparison to other ethnic minorities in the sample group (Peters et al, 2009). Cemlyn et al (2009) and Smith & Rushton (2013) concur with these findings suggesting that inequalities experienced through economic and social exclusion, poor education, health and housing conditions cause the increased health problems experienced by Gypsies and Travellers.

The mobility of Gypsy and Traveller lifestyles is influential but not exclusively responsible for the difficulties faced by this group of people. For those following a nomadic lifestyle the health related issues are twofold. There are the difficulties in accessing health care as a result of frequent evictions and constant mobility, which makes it difficult to register with a doctor as time spent in any one location is limited (Jesper et al, 2008; Matthews 2008). For these families medical help is usually accessed through hospital Accident & Emergency departments. The outcome of this approach is a lack of consistent medical care or of medical history being developed to identify or follow patterns of illness or behaviours. The other significant factor is the environmental risk from living at inappropriate roadside stopping places or unauthorised sites. These health risks can include accidental injury,

particularly to children, increased risk of caravan fires and of respiratory and communicable diseases (Clark & Greenfields, 2006; Smith & Rushton, 2013).

In comparison, housed Gypsies and Travellers may be able to access a doctor more easily as they have a permanent address (Traveller Movement, 2012, Aspinall, 2014). However, living in a house brings its own problems for a traditionally nomadic community. Parry et al (2004) suggest that settled or housed Gypsies and Travellers have poorer health than those following a mobile lifestyle, particularly psychological problems attributed to the lack of mobility and loss of traditional mobile lifestyle. Greenfields (2008:15) concurs with this view suggesting the reason for this is *'cultural dislocation',* in which the change in cultural lifestyle, aversion to bricks and mortar, loss of mobility and often being separated from close family members promotes feelings of isolation. This isolation from the Gypsy and Traveller community is often exacerbated by experiences of prejudice and discrimination causing isolation from the sedentary community as well as fear of social integration.

Cemlyn et al (2009) proposes that appropriate accommodation underpins access to health services. This continues to be reiterated in more recent studies by Smith and Rushton (2013) Greenfields and Lowe (2013) and Greenfields, Cemlyn & Berlin (2015). The example of maternal health amongst Gypsy and Traveller women demonstrates this with particularly poor maternal health attributed to the highly mobile nature of the community (Parry et al, 2004, Parry et al 2007; Matthews, 2008) .However there is some contradictory evidence from Parry et al's (2004) findings that settled or housed Gypsies and Travellers have the poorest health. Therefore it is necessary to explore the dichotomy between the delivery of services within the settled and mobile communities, recognising that whilst accommodation is significant to accessing services there is clearly also a need for flexibility in health provision to improve services and access to health care for the mobile community. Accessing health care is therefore not just about location and physical proximity, consideration also needs to be given to cultural attitudes and behaviours that prevent access

to health services (Van-Cleemput, 2010, Dar et al, 2013; Greenfields, Cemlyn & Berlin, 2015).

Provision and access to health services

Parry et al (2004) suggests that there is a contradiction between demonstrable health need and service provision for Gypsies and Travellers and that despite being a community with significant health needs they are accessing fewer services. The mobility of some members of the Gypsy and Traveller community is cited as a focus of difficulty in accessing services and whilst this is a significant barrier it does not explain the continuing lack of access for settled Gypsies and Travellers highlighting the need to explore wider issues of inequality. Platt (2011:1) suggests that inequality can be defined as '*lack of opportunity'*; positing that this lack of opportunity can include restricted access, outcomes and entitlements and that the perception of equality and inequality within society is linked to political and societal views of social mobility. Platt's views are pertinent to Gypsies and Travellers, who whilst in theory have the same entitlement to health services as the mainstream population, research findings suggest that they do not to make use of services (Van Cleemput, 2010; Rushton & Smith, 2013; Aspinall, 2014).

For example Mathews (2008) cites complex and multi-factorial reasons for poor experiences with health service providers including discrimination, marginalisation leading to a lack of trust in health service professionals. Likewise Peters et al (2009) suggest that experiences of exclusion and discrimination are linked to ethnic status and racial discrimination by the majority population creating barriers to accessing health services across all Black and Minority Ethnic groups (BME). This lack of access to and use of services across BME groups is often interpreted by service providers as a social and cultural preference rather than recognition of a health inequality (Stuart, 2008; Harriss & Salway, 2008). It is noteworthy that ethnic health inequalities are discussed in a number of government reports and initiatives including *Tackling Health Inequalities (*2004) and *Tackling Health Inequalities in infant and*

Maternal Health Outcomes (2010) which focus on Black and ethnic minority communities but fail to specifically identify Gypsies and Travellers. However Bhaji & Salway's (2008) report on ethnic inequality in maternity services notes that there are inequalities in maternity services between the mainstream white population and ethnic groups with some being more disadvantaged than others. Whilst the main focus of Bhaji & Salway's report is on Black ethnic minorities the report does also recognise the difficulties faced by Gypsies and Travellers because of the mobility of their lifestyle and that national health services (NHS) are not designed to meet the needs of a mobile community.

The report concludes that differentiated services contributed to inferior maternal and infant health outcomes for ethnic minority groups and that health professionals' lack of training and understanding of diverse patient needs suggests that NHS policy demonstrates commitment to equality but that practice does not meet the needs of ethnic minority groups, implying a rhetorical recognition in policy that is not evident in practice. Van Cleemput (2007) argues that Gypsies and Travellers experience both health inequalities and health inequity defined by the difficulties of their lifestyle. Platt *(2011: 5) a*sserts that '*inequality brings social costs'* suggesting the need to look beyond apparent difficulties in provision of services. It is arguable that in terms of social cost the widespread inequality and inequity experienced by Gypsies and Travellers is resulting in a significant disparity in health, wellbeing and mortality in comparison to the sedentary population. The juxtaposition of social and health inequality is further endorsed by the Marmot review (2010) which posits that social and political cultures influence health inequality citing ethnicity and education as predominant factors. The Marmot (2010) review also recognises the importance of the environment and community in promoting and inhibiting positive health outcomes, identifying all the key issues relating to the health and wellbeing of Gypsy and Traveller communities with indisputably clear evidence of the social inequalities all of which are experienced by Gypsies and Travellers.

Parry (2004) recommends specialist health workers as one way of improving the health services for Gypsy and Traveller communities. Whilst Van Cleemput (2007) argues that mobility is a lifestyle choice, questioning whether mobility entitles Gypsies and Travellers to a specialist health service and positing that a specialist service may actually isolate the Gypsy and Traveller community further. However there is clearly a consensus that there is a need for improved access to services and for culturally appropriate services provided by culturally competent staff (ITMB, 2012). Therefore perhaps specialist service should focus on the cultural competence of staff to improve the experience and confidence of Gypsies and Travellers to access services rather than a specialist service that keep the community isolated. Goward (2006) Mathews (2008) and Stuart (2008) concur with the view that health service provision should be broad and community focused encompassing all the contributory factors influencing health difficulties.

Whilst there are significant external barriers to accessing health services for socially disadvantaged groups it is essential to consider the role that personal relationships, both of close family and community, play in influencing health and wellbeing. Defined as '*social capital*, Marmot (2010: 24) suggests that access to close relationships between individuals promotes resilience and provide barriers to health risks. Close relationships within Gypsy and Traveller communities might suggest high levels of resilience but the significance of health problems including bereavements and the gendered roles and responsibilities suggests otherwise (Hodgins et al, 2006; Greenfields, 2008; Cemlyn et al, 2009).

Gender, Ethnicity and Health

There are striking differences in the patterns of morbidity and mortality between men and women, influenced by biological, environmental factors and socio- economic status, with those from the lower socio economic groups the most vulnerable to poor health and higher mortality rates (Mustard, 2003; Rogers et al, 2010). Additionally men are more at risk from occupational accidents and injuries and women more likely to experience mental health

problems, domestic violence and higher levels of maternal mortality (Equality & Human rights Commission (EHRC), 2010; Marmot, 2010). Behavioural attitudes and expectations are also influential, gender stereotypes of men being strong and not emotionally demonstrative may result in the repression of symptoms and unwillingness to acknowledge illness, whereas women, viewed as more vulnerable and emotive are more responsive to illness and seeking external help. Whilst there are clear biological influences with men and women susceptible to different diseases attributed to genetic and hormonal differences it is perhaps the socio cultural and socio economic influences of gender role behaviours that have the greatest impact on health and mortality (Field et al, 1997; Marmot, 2010).

Consistent with this theme there are distinct differences between the health and mortality rates of Gypsies and Travellers and the general populations of England, Wales and Ireland. As an ethnic minority with low socio economic status the life expectancy of Gypsies and Travellers remains lower than that of the majority population. Brack and Monaghan's (2007) findings suggest that 50% of Irish Travellers die in Ireland before their thirty-ninth birthday and 70% before the age of fifty-nine years. This highlights a stark difference in life expectancy, fifteen years lower for men and eleven and a half years lower for women Travellers than the general population in Ireland (AITHS, 2010). There is no comparable national data for Gypsies and Travellers in England and Wales but Cemlyn et al (2009) found some regional data gathered from Gypsy and Traveller accommodation needs assessments (GTAA) which emphasised the differences in life expectancy of Irish Travellers and English Gypsies with some English Gypsies having similar life expectancies to the mainstream population, this is attributed to those living in secure accommodation with access to health care. The Cambridge GTAA found 12.9% of respondents were over the age of 65, the majority were English Gypsies, compared to 16 .5% of the general population for the area (Home & Greenfields, 2006). Similarly the East Kent GTAA found 22% of English Gypsies but only 10% of Irish Travellers over sixty years old (Richardson et al, 2007). Hence the statistics from Ireland are slightly lower than those of England and Wales.

More recent data from Buckinghamshire GTAA shows a static rather than improving mortality profile with only 9.8% or one in ten of the sample over sixty years old (Moore et al 2013). There are similar comparisons to be made with First Nation populations, for example the life expectancy for the majority populace of Australia is approximately twenty years more than that of indigenous aboriginals, the life expectancy of whom is approximately sixty years of age for men and sixty eight years for women. This confirms that gender differences in mortality and socio economic status have a significant impact on the life expectancy of minority ethnic groups (Office National Statistics (ONS), 2014; World Health Organisation (WHO), 2014).

Similarly there are differences in leading causes of death both by gender and ethnicity. Biological illness in the forms of cancer and circulatory diseases are the leading causes of death within mainstream populations for both men and women, this pattern is also consistent for Gypsy and Traveller women for whom circulatory disease is the main cause of death. However this is not the case for Gypsy and Traveller men for whom the leading modes of death are attributed to external and environmental factors, with suicide as the main cause of death followed by road traffic accidents and violent deaths (Brack & Monaghan, 2007; AITHS, 2010). Although male suicide is a significant cause of death in mainstream society it is not the leading cause of death as it is for Irish Travellers in Ireland where male suicide is 6.6% higher than in the general populace.

The AITHS (2010) study also found higher levels of morbidity in Traveller communities than in the majority population, with similar findings identified by the 2011 census for England, thus confirming that the health status of Gypsies and Travellers is the poorest of all ethnic minority groups. The study also identified that only 70% classified their health as good in comparison with 81% of the general population (ONS 2014). Furthermore Aspinall' s (2014) study of the limited national data sets available for vulnerable groups found that Gypsy and Traveller men had the highest ratio of long term illness of all ethnic groups, being twice that of the white British illness ratio. Likewise Parry'et al's (2004) earlier study of the health status

of Gypsies and Travellers in England also found specific variants in the health of Gypsy and Traveller men and women that were not found in the comparator ethnic cohorts of English (from similar socio demographic backgrounds), Pakistani, and Afro –Caribbean origin, most notable were high levels of anxiety, found in 44% of women and 30% of men and depression found in 27% of women and 11% of men.

Reflecting on these statistics it is evident that not only do Gypsies and Travellers have significantly higher morbidity and mortality rates than those of the mainstream society; there is also a clear gender divide in both life expectancy and mode of death. Although mortality rates are higher than the general population the underlying causes of death follow similar gender based patterns. Likewise patterns of morbidity are consistent with gender norms as women are more susceptible to mental health issues namely depression and anxiety than men, and men are less likely to seek medical help until illness is serious and the status of health is compromised.

Maternal and child health

Today antenatal care ensures that maternal and child death in the UK is rare. The Office of national statistics (2014) and Department of Health (2010) report a continuing decline in infant mortality rates over time, currently with 3.9 deaths per 1.000 live births. However this is not the case for Gypsies and Travellers. The Confidential Enquiry into Maternal Deaths (Lewis & Drife, 2001) found that the maternal mortality rate is disproportionate when compared to the sedentary population. This trend continues with both infant and child mortality rates being significantly greater than the mainstream population with 29% of Gypsy and Traveller women experiencing a miscarriage in comparison to 16% of the sedentary population and 17% experiencing the premature death of a child in relation to 0.9% of the sedentary population (Parry et al, 2004). Parry's findings suggest that the infant mortality rate within the Gypsy and Traveller community is also twice that of the sedentary community. Baker (2005) suggests that infant mortality is in fact three times that of sedentary population

further illustrating the difficulties in gaining accurate data on this community. Whilst the accuracy of data may be questionable there is clearly no doubt that there is a significant difference in infant mortality between the Gypsy and Traveller and sedentary communities.

Further evidence of high infant mortality is found in Ireland where infants born to Travellers are 3.6 times more likely to die than infants in the general Irish population (AITHS 2010). Baker (2005) attributes the high infant mortality to poor living conditions, road traffic accidents, low immunisation rates and poor access to pre and post-natal healthcare. Both Parry et al (2004) and Cemlyn et al (2009) confirm this and cite additional factors including most significantly the mobility of the community and frequent evictions increasing the risk to Gypsy and Traveller women of both maternal and child death. However whilst there is clearly a significant difference in mortality rates these figures need to be recognised within the context that whilst mortality rates are higher in Gypsy and Traveller communities so is the number of children within each family, Romany Gypsy women having an average of 3.5 children and Irish Traveller women 5.9 children across their lifespan in comparison to 1.7 in the sedentary population (Cemlyn et al, 2009). Hence whilst there is a difference in family size there is also a difference in the maternal care received by Gypsies and Travellers and the sedentary population, with highly mobile women particularly less likely to access antenatal care throughout their pregnancy (Lewis & Drife, 2001; Lewis 2007; Cemlyn et al, 2009).

Some explanations for the high maternal and infant mortality rates can be found in a number of Department of Health reports including the *Implementation Plan for Reducing Health Inequalities in Infant Mortality: A Good Practice Guide (DH 2007)* and *The confidential enquiry into maternal deaths, Saving mothers lives (Lewis 2007) and Tackling health inequalities in infant and maternal health outcomes (DH, 2010) and Reducing infant mortality in London An evidence-based resource (Korkodilos & Omonijo, 2015).* Although the reports do not specifically refer to Gypsies and Travellers as vulnerable and disadvantaged ethnic minorities all of the identified risk factors are pertinent to Gypsy and

Traveller lifestyles. For example the reports identify the women most at risk from maternal death as those from disadvantaged and excluded groups in society citing multi-factorial problems including poverty, poor health, domestic violence and homelessness, (Gypsies and Travellers are legally homeless if mobile or living on unauthorised sites (Clark & Greenfields, 2006)), as key risk factors for maternal morbidity (Lewis,2007). Furthermore women from these backgrounds are less likely to access maternity care until late in pregnancy, 17% of maternal deaths had accessed maternity services within the final four months of pregnancy and had less than four antenatal appointments. Evidence to support these findings in relation to Gypsies and Travellers was found throughout the research reports by the House of Commons Health Committee (2003) Parry et al (2004), Greenfields (2008), Matthews (2008) and Cemlyn et al (2009) all of which recognise the barriers to accessing maternity services for travelling women,

In addition to the factors above the age of the mother is also significant with infant mortality rates 60% higher for teenage mothers than mothers aged between twenty and thirty- nine. Teenage mothers are also 25% more likely to have premature or low birth weight babies compared to older mothers. The main contributory factors are that young mothers are more likely to have poor diets, smoke and are less likely to breastfeed (DH 2010; Public Heath England, 2014). Once again these are significant factors for Gypsy and Traveller women who marry young and have long child bearing lives, starting as teenage mothers thus putting them at greater risk both as young and older mothers. Thus both maternal and infant mortality is '*shaped by social and ethnic differences'* (DH 2007). Further evidence linked to ethnicity and in particular the nomadic lifestyle can be found in comparative studies with Canadian and Australian aborigines who have similarly high infant mortality rates attributed to socio and environmental lifestyles (Hodgins, 2006)

In terms of bereavement the potential for unresolved grief and need for bereavement support is substantial given that miscarriage and stillbirth are often not recognised publically, as loss

needing to be grieved outside of the immediate family (Lovell 1997), perhaps accounting for the significance of depression and anxiety found amongst Gypsy and Traveller women.

Mental Health

'There is no health without mental health' (DH 2011), this statement recognises that poor mental health may lead to poor physical health; a view that underpins the current mental health strategy which acknowledges that mental health issues remain problematic as mental illness often carries with it stigma and taboo (DH2011). This reluctance to discuss mental health issues is particularly prevalent in Gypsy and Traveller culture, where mental illness is feared and referred to secretively by culturally specific terms, amongst these "mental" being used to define "madness" and more common mental health conditions are typically referred to as '*nerves*' (Parry et al 2004:52), The full extent of mental health related problems are often hidden or dealt with by self-medication through the increased use of drugs and alcohol (Matthews 2008). Therefore it is difficult to accurately assess the extent of mental health problems experienced by Gypsies and Travellers. Goward's (2006) report looking at the mental health status of Gypsies and Travellers found that the majority of those interviewed felt unable to seek help within the community suggesting that the large family structure can be an advantage or disadvantage, both supporting and hindering engagement with mental health services.

The government report, *No Health without Mental Health: A cross-Government mental health outcomes strategy for people of all ages, Analysis of the Impact on Equality (AIE) (2011)* very positively, given the general invisibility of the population, recognises the difficulty in accurately measuring the extent of mental health problems for Gypsies and Travellers citing the lack of statistical data and the invisibility of Gypsy and Travelling communities as reasons for this under-diagnosis and treatment. Nonetheless the report does suggests that Gypsies and Travellers are nearly three times more likely to experience anxiety and just over twice as likely to be depressed than the mainstream population, with women

twice as likely to experience mental health problems as men, confirming the findings of Parry et al (2004). Furthermore the report recognises the impacts of inequality on mental health stating that the lowest socio economic groups have a higher risk of developing mental health problems with mental illness 2.7 times more common in men and 1.4 times more common in women than in higher socio economic groups. The higher risk factors associated with low socio economic status are based in inequality and related to increased stress, financial difficulties and poor living environments (DH 2011). Given that Gypsies and Travellers fall into this category they are clearly at greater risk.

Findings from both Parry et al (2004) and Cemlyn et al (2009) cite discrimination experienced throughout the lifespan as an underlying cause for the high prevalence of anxiety, depression, and suicide. Other key factors influencing mental health include the loss of a parent, notably the loss of a mother, which are found to have long term effects on women's lives (Goward et al 2006). Moreover Richardson et al (2007:113) provide an example of a fifty year old woman who with the loss of her mother became the family matriarch, thus demonstrating the intensity of loss, and the impact that shorter life expectancy has on Gypsy and Traveller families with the loss of role models and support from older generations:

'*When you lose your mother your head of the family, you've lost your mentor so you have to fill a pair of shoes as well as grieve a pair of shoes'*

The above statement highlights the challenges Gypsy and Traveller women face in terms of both providing and receiving family and community support. As such the impact of maternal mental health on the growth and development of children needs consideration, when seeking to support the Gypsy and Traveller population as Allen (2011:16) posits that '*the roots of mental health problems lie in childhood'.* Mothers with poor mental health, for example triggered by bereavement and complicated grief, are five times more likely to have children with mental health related problems such as emotional and behavioural difficulties

(Meltzer et al 2004). Moreover evidence suggests that there is a cyclic pattern of influences between childhood and adult mental health with the impacts of adults with long term mental health traced back to childhood beginnings (Social Care, Local Government and Care Partnership Directorate, 2014). As many as 50% of adult mental health problems start before the age of fifteen and 75% by the age of eighteen (Lemer, 2013). This suggests that not only do mental illness and bereavement have a detrimental effect on the health and wellbeing of adults but also on development of any children they care for.

Suicide

'In most cases, suicide is a solitary event and yet it has often far-reaching repercussions for many others. It is rather like throwing a stone into a pond; the ripples spread and spread.'
(Wertheimer 2001)

Wertheimer refers to the far reaching effects of suicide, with the ripple effect referring to evidence that a family history of suicide increases the risk of death by copycat or bereavement related suicide. For Gypsies and Travellers, as noted above, the experience of bereavement and loss is intense as families and communities are very close. Wertheimer's ripple effect has a powerful impact with some relatives of suicide victims becoming predisposed to suicide themselves. Walker's (2008) findings suggest that forty per cent of Irish Traveller suicides were as a result of a close relative also committing suicide.

This supports the suggestion that suicide is a learned behaviour and used as a strategy to relieve stress and anxiety. The causes of suicide are complex resulting from biological, genetic, psychological, sociological and environmental factors (World Health organisation (2011). Thus the increased risk factors predisposing someone to commit suicide include mental illness; alcohol and drug misuse; and stressful life events such as unemployment, imprisonment, death or divorce (National Mental Health Development Unit (NMHDU) (2009;WHO, 2014; HM Government,2015). McKenzie & Bhui (2006) also include racism and socioeconomic status amongst the increased risk factors. Therefore a high suicide risk

would be typically represented as a person with a combination of risk factors including mental health problems, usually depression, a traumatic loss, typically bereavement or unemployment and the effects of coping behaviours such as alcohol and substance misuse which add to rather than alleviate problems (Walker 2008; WHO, 2014; HM Government, 2015). It is noteworthy that all of the identified risk factors associated with increased risk of suicide other than divorce (although this is increasing within the Gypsy and Traveller community) are all prevalent issues for the Gypsies and Travellers. Thus the vulnerability of multiple risk factors and lack of access to health care support puts Gypsies and Travellers at high risk of suicide, a theoretical model borne out in the emergent findings of this study.

Walker (2008) cites Durkheim's (1952) suicide theory which posits that the impact of social change including the loss of traditional beliefs and practices is the predominant influence in suicide attempts. This theory would fit patterns found in more recent studies of suicide in Australian Aboriginal people and Native Americans. For example Tatz's (1999) study of Australian Aboriginal youth suicide identified the aboriginal population as marginalised and having the poorest heath, higher infant mortality and lower life expectancy than the mainstream Australian population, all traits that are found within the Gypsy and Traveller population. Cemlyn et al (2009) endorse this similarity by making comparisons between the socio economic circumstances of Gypsies and Travellers and Native Americans and Australian Aboriginals as communities experiencing racism and enforced change from traditional cultural lifestyles. Walker (2008) also confirms the links between the loss of tradition and culture and high suicide rates within some ethnic minority communities elsewhere in the world including Australian Aboriginals, Native Americans and some Hispanic groups. Conversely African Americans have a noticeably low suicide rate; this is attributed to close knit communities with strong family and religious beliefs. Smyth et al (2003) however, argue that culture both protects from suicide risk and acts as a facilitating factor in vulnerable communities. For example ethnic groups with a culture promoting a strong ethos of family and religion were found to have strong protective factors against

suicide however discrimination and prejudice increased the risk factors overriding the protective elements. Walker (2008) suggests bereavement is an additional facilitating risk of suicide. Within Gypsy and Traveller communities both protective and risk factors are evident however the facilitating risk factors with high rates of suicide and the vulnerability of cultural change far outweigh the protective factors that strong family and religious values provide automatically placing them in an at risk category.

The substantial erosion of traditions and beliefs and the resultant loss of identity within these groups resulted in increased links between suicide and substance misuse. However a stronger correlation which can be linked to unresolved grief, cycles of death, poverty and social exclusion was found more likely to add to suicide attempts (Tatz, 1999; Cemlyn et al, 2009). Therefore Gypsies and Travellers remain one of the most vulnerable and high risk groups of suicide as a significant cause of death. Furthermore suicide is particularly prevalent amongst Irish Travellers being the second highest cause of death within this community (Walker 2008).

Suicide is a major preventable cause of premature death (World Health Organisation 2011) but remains a significant cause of death in both the general population and Gypsy and Traveller communities. The national statistics for suicide, discussed earlier in this review, show the average ratio of suicide between men and women is approximately three male suicides to each female. However it must be noted that the data for England is for the general population and whilst it is probable that the figures include Gypsies and Travellers to some extent they are not specifically identifiable. Mckenzie and Bhui (2006) note that whilst there is some limited data on black ethnic minority groups there is a distinct lack of data for white ethnic minority groups despite concerns relating to the high rates of Irish and Scottish suicides in London. Cemlyn et al (2009) cite evidence from the Irish Traveller Movement, of high incidences of suicide within the Irish Traveller community. It is arguable that there is a correlation between the evidence of a high number of Irish suicides and the Irish Traveller community in London.

In contrast to the figures for England, Walker's (2008) report documents the prevalence of suicide amongst the Irish Traveller community in Ireland between 2000 and 2006.The findings are striking, identifying the suicide rate of Irish Travellers being three times that of the general population in Ireland at 3.70:10,000. The ratio of male to female suicide is higher than figures for England with male suicide four times as common as female suicide. Over sixty five per cent of Irish Traveller suicides were under thirty with hanging the most common method of suicide. More recently, *The all-Ireland Traveller health study* (AITHS) found that the suicide rate of male Travellers was 6.6 times that of men in the general population in Ireland and accounted for 11% of all Traveller deaths (AITHS, 2010).

Walker's (2008) study identified key indicators for the suicides within the Irish Traveller community; of which bereavement suicide was the most common. One third of the deaths in the study were attributed to the recent loss of a close relative. Alcohol and substance misuse was found to be a precipitating factor in these deaths. Concurrent evidence of the significance of alcohol and substance misuse in relation to bereavement has also been identified by Parry et al (2004) and Cemlyn et al (2009). Other factors influencing the suicides were domestic violence, and 'shamed' suicide, those linked to criminal activity that brought shame on the family. Prison suicides are significant and linked to shamed suicides. Although there is no specific evidence relating to Gypsies and Travellers a key focus of the National Suicide Prevention Strategy relates to prison suicides and identifies high risk groups as young males and those: '*vulnerable individuals ....whom have experienced negative life events'* (NIMH 2007:5) Gypsies and Travellers fits this description as anecdotal evidence suggests that there are large numbers of young Gypsy and Traveller men in prisons.

This section of the literature review has focused on the difficulties Gypsies and Travellers face across all aspects of their life experiences as a marginalised ethnic minority group. The recognition of the increased inter- connectedness of bereavement and generally poor health outcomes are acknowledged by both Parry et al (2004) and Cemlyn et al (2009) who

recommend further research into the effects of bereavement on health for Gypsies and Travellers. Furthermore Van Cleemput (2007) suggests that the lack of access to medical services and the stigma attached to mental health related issues within the Gypsy and Traveller communities increases the probability that bereaved families will share anti-depressants or use alcohol to cope with grief. Evidence from Cemlyn et al (2009) found that Gypsies and Travellers who do access formal medical support following bereavement were typically prescribed medication and not offered counselling resulting in a lack of awareness of or access to bereavement services, further strengthening the evidence suggesting the need for targeted bereavement support services for Gypsies and Travellers (Richardson, 2007).

Gypsy and Traveller death rituals and beliefs

Bereavement for Gypsies and Travellers appears contradictory, with overt expressions of loss, lavish funerals and complex death rituals, whilst grief itself stays firmly hidden and often unresolved for many years (Richardson et al, 2007; Cemlyn et al, 2009). In order to understand this phenomenon it is necessary to understand the close knit nature of the Gypsy and Traveller families defined through their collective culture with each person recognised through their family and kinship group rather than as an individual (Liegeious, 2005). Gypsy and Traveller families and communities live in close physical proximity, typically families will see each other on a daily basis making the loss of a close relative particularly intense not just for the family but also for the wider Gypsy/Traveller community (Davies, 2002; Clark & Greenfields, 2006). The depth of grief can be so severe that the bereaved go into long periods of mourning leading to depression with some Gypsies and Travellers claiming they '*never get over it' (* Richardson et al, 2007:99). This intensity of feeling makes death a very important part of Gypsy and Traveller lives, demonstrated through a deep commitment to and respect for both those approaching the end of their lives and the dead. The concern for the community is particularly evident in the level of care and respect given to the elderly who are placed in the highest esteem within the community

(Okely, 1983). The anticipation of loss is openly expressed by younger family members who fear for the loss of older relatives (Greenfields 2008).

Family honour and respect are fundamental values within Gypsy and Traveller communities, both in life and impacting on the shape of death rituals. The position in community and respect for deceased is measured by the length of the funeral procession. Consequently funerals are large and elaborate gatherings where family and associates travel long distances to attend and pay their respect to the deceased. Graves are often ornate with large headstones often including a photograph or a symbolic image representative of the life of the deceased such as horses or wagons. Such graves are well cared for with regular visits made to graveside particularly on the anniversary of the death, birthdays and religious holidays, thus maintaining the place of the dead amongst the living (Clark & Greenfields 2006; Okely 1983; Parker & McVeigh; 2013).

Death rituals and beliefs are influenced by cultural heritage and tradition, of which many are linked to religion (Liegeios, 2005, Okely1983). This is particularly evident amongst English Romani Gypsies and may include a strong belief in ghosts (or '*mulo*'). Often death rites are designed to protect the living from the return of the ghost or spirit of the deceased, as in the practice of 'sitting up' or not leaving the deceased alone from the moment of death until the funeral and in the destruction of the deceased's belongings. Historically all the possessions of the deceased would have been burnt, but today the trailer and any valuables are more likely to be sold to the non Gypsy (Giorgio) population. Furthermore Okely (1983) suggests that the practices of the destroying possessions and the destruction of property are also linked to the belief that deaths (and birth) are polluting events and the burning of belongings is a cleansing process. Often, the deceased is not mentioned again by name after death, instead referred to by the relationship to another family member, such as Mary's dad. Photos of the deceased are also often removed from the public view, which Okely (1983) suggests is to prevent the return of the '*mulo*'. However, Clark & Greenfields (2006) advocate that it is more likely that the intensity of loss leads to the removal of photographs

as they are too painful to look at for surviving relatives. In addition the itinerant nature of Gypsies and Travellers means that when a family member dies the remaining family often move away from the area, although this is becoming increasingly difficult as the number of housed Gypsies and Travellers increases and house moves become more complicated. Finally highlighting the centrality of death within Gypsy and Traveller heritage is the importance of the physical place of death which holds particular significance. In contrast to sedentary society where the place of birth is a primary marker for identity for many Gypsies and Travellers it is their last resting place. Further insight into understanding these death rituals and beliefs is provided by Williams' (2003) study of the French 'Manus' Gypsies. Williams outlines the traditions surrounding 'the *silence of the living and the voices of the dead',* explaining how although the dead are banished they remain constant in the lives of the living. Although the name of the deceased may not be spoken, memories, stories and visits to the graveside keep the deceased an integral part of the family.

In view of the complexities of Gypsy and Traveller lifestyles, bereavement and loss within this community results in a continuum of loss and potentially complicated grief that underpins many of the physical and mental health problems experienced throughout their lifespan, exacerbated by the minority ethnic status, cultural traditions and beliefs (Worden, 2003; Parry et al, 2004; Cemlyn et al, 2009).

Chapter summary

This literature review has supported the aims of the research by highlighting the development and change in how bereavement is managed within society with reference made to differing cultural approaches, providing a context for bereavement in Gypsy and Traveller families. Furthermore part two outlines the distinct cultural norms and community practices that underpin Gypsy and Traveller lifestyles and experiences', understanding these provides a rationale for the bereavement behaviours identified in the study.

Drawing conclusions from the literature review previous research relating to Gypsies and Travellers focuses on accommodation, health and education. Anecdotal outcomes of some of these reports, such as Parry et al (2004), Richardson et al (2007) and Brack and Monaghan (2007) have identified high levels of bereavement and mental health problems (potentially associated with complicated grief reactions), that impact on health and wellbeing of individuals within these communities, suggesting a need for further research in this area.

Whilst bereavement experiences are under researched within Gypsy and Traveller communities there are a plethora of bereavement research studies focused on mainstream populations, many of which take a qualitative and phenomenological perspective such as Dyregov's 2004 study of bereaved parents, Begley and Quayle's (2007) study of adults bereaved by suicide and Sandage's (2009) study of intergenerational suicide in the American prison population. The use of a phenomenological research framework in the bereavement studies mentioned above provides validation for using hermeneutic phenomenology, or the interpretive study of lived experiences, as an appropriate choice for this study (Dressman, 2008).

The following chapter discusses the research methodology and process used in this study, including the recognition of bereavement research as a sensitive subject and the ethical principles that have underpinned the choice of methods and design of the research.

Chapter 3: Research Methodology

Introduction

This chapter begins by re-visiting the aims of the research before discussing the rationale for the research paradigm and methodology chosen for this study. The research framework has a phenomenological approach using narrative inquiry to gather life story experiences (Cresswell, 2013). This approach aims to validate ordinary experiences by focusing on the everyday lived experiences of individuals. Phenomenology seeks to describe people's perceptions, attitudes, beliefs, feelings and emotions, presenting these as authentic and meaningful experiences by '*seeing things through the eyes of others'.* Denscombe, 2014:94). Thus the phenomenology of bereavement, or lived experiences of bereavement are explored through the narratives, or stories told by bereaved individuals (Rosenblatt, 2008). This allows both individual and social group concepts relating to bereavement to be identified while ensuring that the focal point of the research is on the emic perspective of individual experiences (Denzin & Lincoln, 2013; Ritchie & Lewis, 2003). However given the potentially sensitive nature of bereavement as a research subject that may increase the vulnerability of the participants, their wellbeing was paramount to the design and processes of the study and influential in the choice of narrative inquiry as the main research method used (Lee1993, Liamputtong, 2007).

Throughout the chapter discussion will focus on the methods and processes used to meet the aims of the study. The research design has been underpinned by solid ethical principles and values of undertaking sensitive research, which keep the emotional wellbeing of the participants central to the research process particularly as bereavement is an intensely personal and sensitive subject. (BACP, 2010; BERA, 2004; Renzetti & Lee, 1993; Stroebe, Stroebe & Schut, 2003).

Research aims revisited

The research aims to:

Gain an understanding of the cultural norms and community practices influencing the bereavement experiences of Gypsy and Traveller families.

The study explores the impact of bereavement on individuals and wider family members with consideration given to family structure, gender roles and responsibilities enabling the identification of the specific culturally mediated experiences of Gypsies and Travellers. Attention is given to the close cognate kinship and collectivist nature of Gypsy and Traveller communities, and how bereaved individuals are supported in both a family and community context given that death and loss are not typically openly discussed within this ethnic group.

Based on consideration of the above, as the study evolved the following objectives have developed to provide the framework for the research:

- *To identify whether the experience of bereavement has a long term impact on Gypsy and Traveller life experiences (e.g. impacting on expectations of further loss, attitudes towards family members and relationships).*

- *To explore the extent to which community members feel that membership of a close-knit family and community with explicit cultural norms of bereavement and grief offers effective support for managing the processes of loss or potentially exacerbates the risk of long-term complicated grief.*

Research methodology

For this study a qualitative approach has been used. This is defined as a naturalistic approach using interpretive and often multiple methods such as focus groups, interviews and narratives which explore personal experiences, life stories and the social worlds of the participants (Denzin & Lincoln, 1998, 2013). Qualitative research uses small scale purposefully selected samples involving close interaction between the researcher and participants to produce in-depth research which interprets the social worlds, perspectives and life experiences of the participant (Dressman, 2008; Ritchie & Lewis, 2003; Silverman, 2006; Cresswell, 2013; Ritchie et al, 2014).

Furthermore Strauss & Corbin (1990) propose that social research methods, defined as research which explores social processes, the individual in society and social world of the individual, are best suited to research relating to human behaviour and experiences (Bryman, 2012). Thus the nature of qualitative inquiry enables researchers to gain a detailed insight into lives of the participants, through the interaction between the researcher and participant (Cohen et al, 2000; Cresswell, 2013; Denzin & Lincoln, 1994, 2013). This study fits the above approach as the research focuses on identifying and understanding individual bereavement experiences in a specific ethnic group. A qualitative research approach using narrative inquiry, defined as stories relating to experiences that are meaningful and sequential representations of individual experiences was an appropriate choice of method to facilitate the collection of detailed personal accounts of the participant's behaviours, experiences and socio-cultural world in relation to bereavement (Bold, 2012; Bruner, 1990; Reissmann, 2008; Wells, 2011).

Hence the focus on participant life experiences draws on a phenomenological paradigm by exploring behaviours and social roles to develop understanding of how individuals interpret and react to their environment (Bryman 2012). Dewey (1998) proposes that experience is personal, social and continual, with past experiences influencing the future. Consequently

participant life stories will have been shaped by both social and cultural behaviours, and the expectations of the community or wider society to which they belong. In this study, life experiences will be shaped by the cultural mores of Gypsy and Traveller communities, which differ from mainstream society (Acton, 1997; Evans, 1999; Bancroft 2005). Moreover, whilst the social world of Gypsies and Travellers will be distinct to their own cultural heritage, as an English Gypsy or Irish Traveller, it will also be shaped by the interactions and experiences from both within the family, community and the wider population. This socio-cultural shaping of behaviour is underpinned by Bourdieu's (1977) concept of '*habitus';* which suggests that learnt behaviours and dispositions developed in childhood influence ongoing lifelong behaviours. Similarly predispositions for behaviour are based in social structures such as, ethnicity, gender and socio–economic status further endorsing the influencing factors shaping life experiences. Hence, '*behaviour and thereby data are socially situated, context related, context dependent, and context rich'* (Cohen et al 2000: 131). Thus the basis of social research is data gathered by naturalistic inquiry, influenced by personal behaviours and situated in a social perspective (Silverman, 2001). In the context of this research, the aim is to understand the meanings which people attach to their actions, beliefs and values through personal bereavement experiences and the impact these elements have on individuals, families and community coping strategies.

Research design

Initially the research was designed with a phenomenological paradigm focusing on an individual psychological approach. The rationale for this was to avoid the culturally stereotypical standpoint of marginalisation and negativity often associated with Gypsies and Travellers. However as the research progressed the focus shifted from an individual focus to a more sociological perspective as it became apparent that socio-cultural factors had an overwhelming influence on individual bereavement behaviours.

The research has been designed to use a range of qualitative methods including semi structured questionnaires, focus groups and individual narrative conversations. The range of methods used was chosen to provide breadth, rigor and reliability to the study. Reliability in qualitative research is often challenged as the data can be subjective and drawn from the behaviours and beliefs of individuals rather than the objective, generalised and statistical approach of quantitative research (Ritchie & Lewis, 2003). In fact there is conflicting discourse surrounding the terminology used to validate qualitative research, eminent qualitative researchers such as Strauss and Corbin (1990) and Lincoln and Guba (1985) suggest that 'credibility' and 'transferability' are more appropriate terms than the traditional quantitative terminology of validity and reliability, whilst others assert that the suggestion that validity and reliability are not appropriate adds further weight to the view that qualitative studies are invalid and unreliable (Lewis et al, 2014). Nonetheless regardless of the terminology used research design and processes must be robust as these measures are used to establish generalisation or transferability of the research findings to suggest similar outcomes if the research were to be repeated. In the case of bereavement research Briller et al (2007) provide an example of how validity and credibility can be established with bereavement focus groups and individual narratives by identifying similarities and themes across the data collected. Similarly for this study common themes and trends were used to validate the study and provide an authentic account of the participant voice, capturing the bereavement experience and support needs of Gypsy and Traveller communities.

The reliability of the study and narrative data collected is dependent on the consistency of the research approach, for example in this study both of the focus groups used the same vignettes (see appendix two), to develop the discussions and the individual narratives were participant led with the researcher questioning and probing limited to gaining clarity of information (Cohen et al, 2000; Denzin & Lincoln, 1998, 2013; Lewis et al, 2014). The reliability of both data collection and data analysis needs verification and, this was achieved through the triangulation of data gathered by identifying similarities and differences from the

group and individual processes. Reliability and validity were gained through member checking by returning the transcripts to the participants to check for accuracy of interpretation (Flick, 2007).A small sample of member checking was carried out as this was not viable with all participants, due to low literacy levels and the mobile lifestyles of some of the participants. Accuracy of interpretation of the narratives was gained through thorough thematic analysis and by an independent analysis of a sample of narratives by a psychologist.

Using narrative inquiry as a research method

As a research method, narrative inquiry uses life experiences and an inductive approach that identifies themes and patterns rather than a deductive hypothesis or theoretical starting point (Reissmann, 2008; Wells, 2011).The narrative or *'stories lived and told'* are derived from the participants personal experiences or life stories, so are '*a highly personal account of real events'* (Clandinin & Connolly, 2000:21; Clandinin, 2013). Thus using stories to make meaning of life experience allows the participants voice to be heard (Thody, 2006). Hearing the participant's voice was fundamental to this study because as a minority ethnic group Gypsies and Travellers who often experience exclusion and prejudice from the sedentary population are without a voice (Okely,1983; Acton,1997; CRE,2006; Powell,2013).It is arguable that the marginalised place held by Gypsies and Travellers in society makes their perceived lack of trust and defensiveness understandable and could be explained as a natural defence or self-preservation built up over many years of prejudicial experiences, creating a reticence to engage with mainstream society (Acton,1997; Bancroft 2005; Powell,2013). This lack of engagement leads to Gypsies and Travellers being labelled as 'hard to reach' communities and their voices being mediated by others rather than themselves (Greenfields & Home, 2006; Ryder, Cemlyn & Acton, 2014).The outcome of this presents potential barriers to research participation because of a suspicion of outsiders, principally authority figures and of how data gathered will be used (particularly identifying

information) (Brown & Scullion, 2009). Understandably there is some caution with research participation, with the need to maintain their separateness paramount.

Okely (1983) highlights some of the challenges of research with Gypsies and Travellers linked to their mistrust of outsiders or non-Gypsies. Citing examples from her own research experience she suggests that when presented with questionnaires and structured interview questions Gypsies and Travellers were '*brilliantly inconsistent'* in their responses, making it difficult to quantify results (Okely1983:39). Clearly the use of a questionnaire with a population with low literacy levels is inappropriate, with the choice of a suitable research method essential to the success of research with Gypsies and Travellers. Okely also advocates participant observation as the most effective research method with Gypsies and Travellers as it allowed her to gain a deep understanding, trust and respect for Traveller lifestyles, which in turn enabled her to gather rich qualitative data by using a naturalistic approach. Her research illustrates the importance of choosing research methods that are appropriate to the participant group and the research focus. Similarly Ryder & Greenfields (2010) found that conversational interview styles were most appropriate and culturally acceptable to Gypsies and Travellers, empowering participants to share their experiences and have their voice heard.

For the participants in this study a questionnaire was not an appropriate method because of the low literacy levels of the participants, the sensitive nature of the bereavement as the research subject and suspicion of paper based data collection methods (Halstead et al, 2008). More importantly, because the research focused on personal experience, narrative inquiry was chosen as the most suitable and practical method as it provides an unobtrusive and empowering means of being able to capture the participant's voice. The narrative approach enabled detailed information about the both the personal and wider context of Gypsy and Traveller life, the participant's social worlds, culture and behaviours, the impact of loss and the voice of the individual to be heard as loss and death is not openly discussed either within the family or wider community. Liamputtong reiterates the value of a narrative

approach in giving voice to vulnerable and marginalised people stating that, '*only the narrator has access to his or her own story…therefore participants uphold authority over their knowledge during the research process'* (Liamputtong, 2007:113).

The narrative approach uses the *'present as a lens to the past'* (Miller, 2000:13) with participant stories reflecting life experiences. This method complements the oral traditions of Gypsies and Travellers who as a historically illiterate group, many of whom still have low literacy levels today, use oral stories to share their history, traditions and life experiences, thus making a narrative approach familiar and comfortable form of expression for Gypsies and Travellers. Ritchie & Lewis (2003) suggest an association between the use of life histories and oral storytelling traditions in research approaches which use symbolic interaction to understand experiences, social action and the environment. In many ways there is little difference between oral storytelling traditions and the use of narrative inquiry for sharing knowledge and experience. In fact Bruner (2002:6) suggests that narrative stories are intuitive with storytelling starting in childhood and that '*story forms a transparent window on reality*'. Similarly Reissmann (2008) suggests telling stories is one of the earliest forms of discourse we learn as children, thus narrative storytelling is a natural form of communication for sharing experiences that starts in childhood. However it is important to recognise that using a narrative approach involves reflecting on the past with stories shared as memories and as such subjective to the reality of the moment in which they are told and the emotional disposition of the individual at the time. This potentially poses a challenge to the accuracy of memory and the story told. Nonetheless the perspective of the participant at the time of the research will be their truth and reality (Lee, 1993; Silverman, 2000; Dressman, 2008).

The information gained through detailed narratives is similar to in-depth interviewing, but unlike most other research methods narrative inquiry does not have a structured framework but uses a conversational approach led by the participant with only minimal interaction from the researcher (Clandinin 2013). This makes it an appropriate method when studying intensely personal experiences (Bell,1999; Silverman, 2006), with the participant as the story

teller rather than respondent the power balances of the researcher and participant relationship changes and the process can be less intrusive than a formal interview process (Holloway & Jefferson, 2000). This is particularly evident in sensitive research studies where the researcher has an empathic and facilitative role which produces a less hierarchical and more conversational style that is central to the narrative process (Miller, 2000; Dickson-Swift et al, 2008). This participatory role is aligned with feminist research principles which suggest that women interviewers are more likely to develop a non-hierarchical and conversational interview style (Oakley, 1981), thus developing a paradoxical role of *'sympathetic listener and friendly stranger'* (Cotterill,1992:596).

Whilst there are clear benefits of participatory research approaches, particularly in sensitive research studies the position of the researcher within the study needs consideration as inevitably the researcher will become involved in and affected by the stories told (Lee, 1993; Valentine, 2007). Liamputtong (2011) discusses the social location of the researcher as influential in developing relationships with the participants, Oakley (2005:230) explains this further using the term '*social distance'*, defined as gender socialisation and life experiences, stating that the closer the social distance between the researcher and participants the greater the researcher bias may be. In this study the social distance between the researcher and participants is fairly wide as are the circumstances of bereavement experiences but as women, wives and mothers the emotional responses to loss are likely to be much more closely aligned. An empathic approach recognising both similarities and cultural differences proved essential to developing a trusting relationship to enable the participants to share very personal experiences, and fundamental to the success of the research (discussed further in the section on the role and reflexivity of the researcher).

Consequently it is subjectivity and personal involvement that creates the discourse that surrounds the credibility of social research studies (Ritchie et al, 2014). Undoubtedly data produced from personal stories is subjective but nonetheless a realistic account of the participant's life experiences from their perspective and as such valid and reliable research

data (Bold, 2012; Clandinin, 2013; Strauss & Corbin, 1990; Silverman 2001). Furthermore Thody (2006) suggests that the challenge with narrative research is in the amount of data produced. The nature of narrative story telling will elicit both useful and useless data as inevitably the story teller will digress from the main point of the story, and that the researcher will only use data that is relevant to the research question. Alternatively the value of a narrative approach is that it enables all the evidence seen or heard to be included allowing for new and different themes and experiences to be identified (Halstead et al, 2008). Within this study the position taken on the amount of data gathered from the narratives concurs with Halstead's point of view; not only does the background information shared often provide a context for the bereavement story but also situates the subsequent behaviours and management of grief processes This additional information also provides an insight into the wider traditions and lifestyles of Gypsies and Travellers and through this identifies additional themes and understanding as illustrated in the following examples:

In one of the narratives the participant related her whole life story; this provided a rich context both personal and cultural for the bereavement story relating to the loss of her son. This background information was useful to providing a wider context to understanding not just the loss of her son but also the loss of contact with her grandchildren following her son's death. The additional information shared here identified multiple losses, not all through death but the loss of several relationships simultaneously. Whilst the researcher's initial focus was on the bereavement story the additional information identified changes in relationships leading to the secondary loss of contact with wider family. For this participant her loss was embedded in her life history and the two are inseparable.

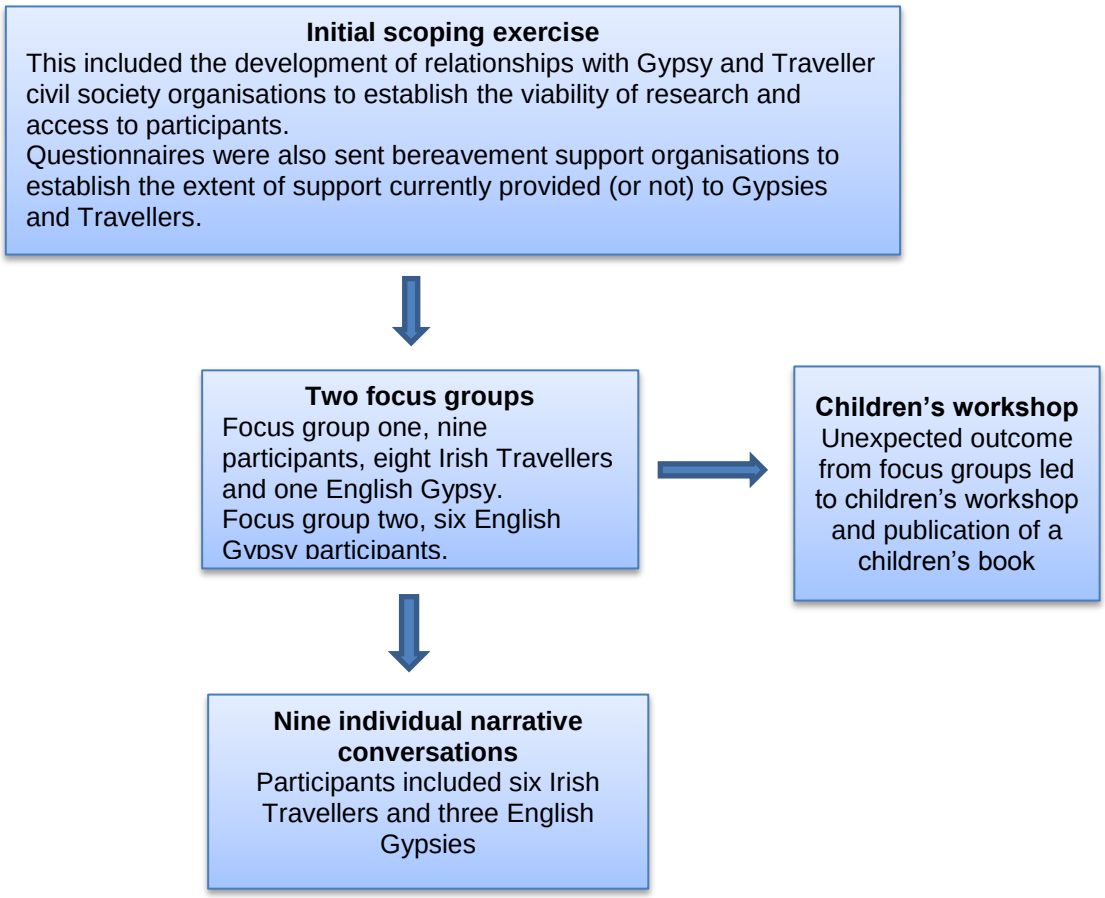
Another older Gypsy detailed her early family life, bringing photographs of family and proudly sharing her family history and heritage. Whilst this could be considered irrelevant to the study content again the background information about family traditions and practices was invaluable rather than irrelevant. But most importantly for this participant someone was interested in her life story. In this case and in all of the interviews it would have been

disrespectful not to listen to the whole story however relevant or irrelevant the information shared. There is a growing evidence base that advocates the importance of Gypsies and Travellers actively participating and engaging in research studies rather than just being research subjects (Greenfields & Home 2006). Taking the time to listen to and hear what is being said is fundamentally important to valuing and respecting the person making the contribution, and ultimately to the success of the research study (Brown & Scullion, 2009; Greenfields & Ryder 2013).

Research process

The following discussion outlines the research process, beginning with the diagram below which illustrates the research design and process, followed by a detailed discussion of each part of the process.

Figure 1. Research design and process diagram



The scoping exercise

The first stage of the research was to undertake a scoping exercise. The aim of which was to explore the viability of the study, to provide background information for the researcher and to facilitate access to participants. This began with an initial consultation with four Gypsy and Traveller support organisations. These are non-government organisations (NGO) that provide advocacy and support to Gypsy and Traveller communities. Any further identification of individual organisations could jeopardise the anonymity of the participants through recognition of their bereavement stories, so has been omitted.

All of the organisations approached fully supported the need for this research using numerous anecdotal examples of multiple and traumatic loss and the impact of multiple bereavements on the health and wellbeing of the families involved. An advisory group was formed with these organisations to establish protocols for the study, which included:

- A Selection criterion for participants, ensuring that potential participants had not recently been bereaved and only including women in the study.

- The provision of neutral venues for the focus groups and narrative interviews to take place.

- Access to additional bereavement support services should participants need it. All of the organisations provide basic counselling support and contact details for specialist bereavement services both nationally and within the participant's locality, were made available.

- Access to participants and facilitation of focus groups. The advisory groups identified potential participants; these were initially women that had taken part in health promotion training or were working with or well known to the organisations.

- Development of vignettes to be used in the focus groups.

Although the main focus of the study centres on the perspective of Gypsies and Travellers, Child Bereavement UK have identified that whilst working with other ethnic minority groups they have not had any involvement with Gypsy and Traveller families. Therefore the second strand of the scoping exercise included a questionnaire survey of bereavement support services and organisations that may have had contact with Gypsies and Travellers, these included Cruse Bereavement Care, The Child Bereavement Network, hospices, Traveller education departments and Gypsy and Traveller Support Organisations, to establish if any of these groups were providing bereavement support to Gypsies and Travellers. A short questionnaire was used for this aspect of the study as the most efficient way to engage with busy organisations (see appendix three). The benefits of using questionnaires as a research tool are that they are an effective method of reaching a wider range of participants and providing a more generalised approach to data gathered (Cohen 2000; Ritchie et al,2014). The questionnaire was deliberately kept short and to the point to maximise the response rate, which was effective with a 75% return rate, (see appendix four for summary of organisations and their responses). Personal contact was made with all the organisations, via telephone conversation prior to sending the questionnaire to explain the research and ask for participation rather than just sending out the questionnaire. The questionnaire responses reiterated the research aims demonstrating limited examples of external support provision for Gypsies and Travellers across a range of organisations, thus illustrating that CBUK were not alone in their lack of contact with Gypsy and Traveller communities. The scoping exercises and initial work completed with the advisory group confirmed the viability of the study. The advisory group of Gypsy and Traveller organisations were also instrumental in identifying the research participants.

Having established the viability for the study through the scoping exercise and formulated the design of the study, outlined in the introduction and the diagram in figure one (page 87), the next stage was to establish the participant population. As an outsider to the Gypsy and Traveller community and the sensitivity of the research topic the establishment of trust was

fundamental to the success of the study. Recommendation by a colleague with a long standing relationships with the organisations generated trust by association for the researcher, enabling the research to take place. The development of trust with potential participants was a lengthy process, taking about six months and requiring numerous telephone calls to build a relationship and for them to be secure that the researcher was sufficiently interested to keep calling back, (see further discussion and interview extract on page 107), highlighting the importance of building trust through perseverance with this ethnic group..

Participant selection & sampling choice

Access to participants was gained through advisory organisations and gatekeepers for the research. Participants for the focus groups predominantly included women who had previously taken part in health promotion programmes with the advisory organisations. It might be argued that there is an element of bias in the participant sample as they have better health awareness and are perhaps more open to need for intervention from external services. However, perhaps as a result of their prior participation in other projects they were t more open to participation in this study. The sample choice was opportunistic, with participants responding to requests made by the advisory organisations.

The research is a study with Gypsy and Traveller women whose ages ranged from fifteen to mid-fifties. This age range provided participants spanning four generations of families, including grandmothers, mothers, daughters and granddaughters, thus giving a perspective of bereavement from different roles and relationships within the same families. The sample choice of only including women was deliberate following recommendations from the advisory group of Gypsy and Traveller support organisations. Given the nature of the research, and the traditional gender role behaviours of Gypsy and Traveller men, it was highly unlikely that men would talk about a subject that they do not talk about within their own community, particularly to a non-Gypsy female researcher (Okely, 1983; Richardson et al, 2007). Therefore as the participants and the researcher were both women and the study focused on

bereavement experiences from the perspective of women, closely aligning to feminist paradigms. Feminist approaches often research sensitive subjects related to the experiences and place of women in society (Oakley, 2005; Dickenson-Swift et al, 2008). Although the place of women in Gypsy and Traveller culture is not the main focus of this study the gender role traditions were influential in the decision to only access women for this study.

Payment for participation

In this study the payment of expenses and a small token of appreciation (£10) for the participant's time was provided as travel expenses were incurred by the participants it seemed only fair to reimburse these. Whilst there are suggestions that payment acts as coercion or incentive for participation, there are stronger arguments in support of the use of payment or reimbursement suggesting that payment demonstrates respect for the individual and equalises the power relationship between researcher and participant and that recognition and respect for those taking part in the study is more important than the payment itself (Holloway & Jefferson, 2000).

'Although payment is often welcomed, we have found simply 'being heard' and involved in research is sometimes worth far more' (Brown & Scullion, 2009: 20).

However, for economically deprived groups such as Gypsies and Travellers reimbursement for time and expenses is a significant factor in enabling research participation, as was the case in this study.

Developing the focus groups

The focus groups were designed using vignettes to provide an initial stimulus for discussion. This allowed the groups to establish and develop the conversation using a generic scenario rather than immediately discussing personal experiences. Furthermore, this approach meant that participants were able to choose to either distance themselves from personal experiences using the vignette as the focal point for discussion or to directly relate their own experiences

to the vignette. The vignettes provided a starting point for the conversations and quickly led to some detailed discussion of the participants own bereavement experiences. These provided a rich source of initial data and identified the similarities and differences in bereavement experiences and perspectives of Irish Travellers and English Gypsies.

The vignettes (see appendix two), were developed from anecdotal life stories and experiences shared by the advisory group using a variety of bereavement scenarios typical to Gypsy and Traveller experiences. These included bereavement by suicide, drug misuse, miscarriage and sudden health related death. Vignettes are defined as illustrations or scenarios describing events (Vargas 2010; Arthur et al, 2014). They are particularly suitable for identifying and assessing specific characteristics; including cultural norms, behaviours, attitudes and feelings (Lavrakas, 2008), thus making vignettes appropriate for researching sensitive subjects (Barter & Renold, 1999). Moreover using stories or vignettes that are contextualised within the research provides an opportunity to discuss sensitive subjects in a less personal and threatening way. Whilst there is the opportunity for participants to create distance through the use of vignettes, inevitably discussing situations similar to personal experiences will indicate how participants will respond in reality (Barter & Renold, 1999).

A focus group is a '*group discussion focused around a particular topic or issue'* (Silverman 2006:164), that is '*shaped by interpersonal dynamics'* (Madriz 1998:160). Although focus groups have a traditional use in market research, this method has become increasingly popular in social research, particularly health care and sensitive research studies (Dickson-Swift, 2008; Finch & Lewis, 2014). Focus groups in social research often adopt a focused conversational style rather than being a more formal group interview aiming to provide greater understanding of attitudes, behaviours and opinions of the participants (Gibbs, 1997). In focused conversations the researcher takes a facilitative role rather than that of an interviewer, placing the emphasis of the discussion on the interaction between participants (Liamputtong, 2011).This approach allows the development of discussions that cover a broad range of relevant issues in sufficient depth to explore the context and perspective of

each participant's response. In addition the shared experiences and opinions of the group are explored, resulting in a reflective, deeper and more insightful level of discussion than an individual interview (Finch & Lewis, 2003, 2014). Thus, there is the opportunity to '*appreciate the way people see their own reality'* (Liamputtong, 2011:6). In this study the information gained provided an insight to and understanding of the socio cultural experiences and heritage of Gypsies and Travellers. This type of focus group is particularly beneficial and increasingly used in sensitive research with marginalised groups and potentially vulnerable participants (Lee, 1993; Liamputtong, 2007). For example, when used with homogenous groups of people, as in this study, there is an opportunity to give a collective voice to marginalised people with the group providing comfort, security and confidence to discuss sensitive subjects through shared experiences (Briller et al, 2007).In addition the conversational or verbal interaction is advantageous over written methodologies for groups such as Gypsies and Travellers who have low literacy levels (DfES, 2009).

The focus groups

Two focus groups took place, in focus group one there were eight Irish Travellers and one English Gypsy and in focus group two, six English Gypsy participants. This provided an almost equal balance of Irish Traveller and English Gypsy participants.

The participants for the focus groups were drawn from clients of the advisory group organisations. Both the focus groups and narrative interviews were held at neutral venues, usually a quiet room in the offices of the advisory groups which were comfortable and familiar to the participants. The duration of each group was approximately one hour. Each group were supported by a facilitator from the advisory organisations. The researcher was the only stranger to the groups as the facilitators and participants had previously worked together on other projects relating to women's health and wellbeing. This and the close kinship and community relationships within the Gypsy and Traveller population meant that the participants knew each other well. In fact in some instances there were some mother

daughter relationships, which meant that an open and relaxed dialogue was quickly established and that discussion moved quickly away from the vignettes into the participants own personal experiences of bereavement.

Focus group conversations allow for both verbal and non-verbal interactions to be observed, including inter- personal and group relationships, which offer an insight into the hierarchy of relationships within the groups (Brakewell et al, 1995). The hierarchy within the focus groups in this study was most evident in the relationships between the younger and older women, with a significantly lower level of interaction and response from the younger members of the group. Reflection on the interactions and responses of the younger participants highlighted a number of possible reasons for their reticent contributions including, a lack of confidence and limited bereavement experiences to share, and finally the relationships with the other members of the group inhibiting participation. While confidence did not appear to be an issue, as their body language was open and relaxed, and when asked directly they readily shared their experiences, consideration was also given to the extent of bereavement experiences of the younger participants. It was clear that they had experiences to share, as when asked their contributions were interesting and mainly related to the loss of grandparents with very vivid memories associated with physical aspects of their experiences, the smells, and coldness of the deceased and expressions of fear, due to a lack of understanding of what had happened. There was a clear age and generational hierarchy within the focus groups following Gypsy and Traveller traditions where older women are highly respected through their matriarchal roles within the family (Clark & Greenfields, 2006). The most likely reason for the behaviour within the group is linked to these hierarchical gender roles demonstrating respectful relationships for older members of the community and not speaking until spoken to, as the younger women responded if asked directly rather than offering information spontaneously (Okely, 1983; Cemlyn et al, 2014).

The discussions provided information from a range of perspectives and relationships, illustrating the protective nature of family relationships, strong peer and community support,

feelings and behaviours relating to the bereavement experiences, which provided an insight into both personal and community practices.

It is noteworthy that many of the respondents commented during their individual narratives that the loss of a family member and feelings associated with such loss are not discussed within the family:

"If it's a member of your own family, your brother or sister, you can't show your feelings, you can't because you are afraid to hurt them, you have to keep a brave face on it" (narrative B).

However despite the comment above and some of the focus group participants being close family relatives the discussions of personal loss were readily shared. Perhaps this was because these were retrospective experiences, although clearly in some cases they had not come to terms with the loss, or because participation in the study provided permission to discuss their loss openly which they were not able to do within their families. This concurs with the findings of Dyregrov (2004) and Briller et al (2007) discussed earlier, who found that participation in bereavement research offered an acceptable place for the bereaved to share their bereavement experiences that was not always available within family and wider social networks.

There were also noticeable differences in dynamics of the focus groups, in focus group one there were some mother and daughter relationships, and all of the participants were familiar with each other. The facilitator from the advisory organisation was an unobtrusive observer in the group. These familiar relationships meant that a relaxed and focused conversation was soon established with the participants leading and developing the discussion. The participants moved very quickly from the vignettes into discussing their own experiences with contributions including shared experience emerging themes relating to personal bereavement experiences and the wider traditions and practices of Gypsy and Traveller life. Whereas in the second focus group the dynamics of the group were very different, individual participants were less confident with each other and literacy levels were lower in this group.

As a result of this the advisory group facilitators took a more active role in leading the group and providing most of the data generated. This group spent longer focused on the vignette scenarios initially generating more general discussion relating the behaviours and consequences of the vignette scenarios in relation to cultural expectations of Gypsy and Traveller communities. Much of the discussion in this group revolved around the differences between Gypsies, Travellers and the sedentary population. This group provided some interesting background information particularly surrounding the death rituals and beliefs of Gypsies and Travellers. The focus groups identified the emerging themes of the research, one of the most significant of these was the recognition that although children are fully involved in all aspects of death rituals and are very well supported physically, there may be a gap in the provision of emotional support for bereaved Gypsy and Traveller children. This outcome led to an unplanned opportunity to extend of the research to include the involvement of children. So alongside the data collection from the individual narrative interviews a two day workshop to consider bereavement experiences from the perspective of Gypsy and Traveller children was established. The following discussion outlines the process of the children's workshop.

The Children's workshop

As stated above an unplanned opportunity arose to extend the research with children as participants, this entailed gaining additional ethical permission to include children in the study and careful consideration of how to manage both the protection and participation of children throughout the research process given the sensitivity of bereavement as the research focus. Therefore a workshop using story, art and photography was designed to explore children's feelings and understanding of death and loss. The stories allowed the children to approach this through the experiences of the story characters rather than drawing on their own experiences which may have caused distress. The use of story allows both *'distancing'* and '*involvement*', as the story framework allows personal identification with the story characters' emotional experiences, thus the story becomes '*a metaphorical reflection*

on life' and a safe space, particularly for children, for the projection of ideas and emotions onto the story characters maintaining an ethical research approach to a potentially sensitive subject (Gersie, 991:16).

The workshop involved seven children and young people between the ages of seven and sixteen, all girls, the workshop not being seen as appropriate or of interest to boys who tend to follow more masculine and male orientated activities (Ureche & Franks, 2007). The children were members of a youth group from one of the advisory Gypsy and Traveller support organisations, some of whom were the children of one of the adult participants. The workshop was delivered over two days and facilitated by a storyteller with significant experience of working with refugees and those having experienced traumatic life events. A photographer was also present to record the workshop providing images for the book *'it's different without you'* (Rogers, 2014) (see appendix 7), produced as a result of the workshop.

Day one of the workshop used songs, stories and art to develop relationships between the adults and children and create a safe environment to enable the exploration of the concepts of death with the children. Day two used more complex story lines and creative activities, including making story sticks and puppets to allow the children to respond to the story content and express their thoughts and feelings about the story characters, enabling them to discuss and demonstrate their understanding of the concepts of death.

This unexpected addition to the research has provided the most tangible outcome of the research so far, the production of a children's book, *'it's different without you'* (Rogers, 2014) (see appendix 7), designed to promote the discussion of feelings following bereavement.

Narrative interviews

Following the focus groups the next stage of the research process was the individual interviews. Nine individual narrative conversational interviews were undertaken to provide more detailed personal accounts of participant bereavement experiences which both reinforced and developed the themes identified in the focus groups. . Six of the interviewees were Irish Travellers and three were English Gypsies. Two of the interviewees were drawn from the focus group participants who provided a much more detailed account of their experiences than the focus group allowed. The remaining seven were identified using snowball sampling. This method uses identified respondents and social networks to provide referrals for additional participants. Snowball sampling is identified as advantageous for increasing the sample size and access to hidden or vulnerable groups by using known respondents with whom trust has been developed to recruit additional participants (Atkinson & Flint, 2001; Brown & Scullion, 2009). In this study the focus group participants referred other family and community members who came forward for the narrative interviews.

The rationale for using a narrative approach is underpinned by the ethical stance of the researcher and the need to be mindful of the sensitivity of the research topic and potential vulnerability of the participants. A narrative approach where the participant has control of the information shared provides a more equal relationship between the participant and interviewer. This was fundamental to this study as a demonstration of respect for the participants, but also as an 'early researcher' was a more comfortable approach than asking structured and potentially intrusive or distressing questions. The researcher's approach of being open and honest to not having worked with Gypsy and Traveller communities before coupled with a genuine interest, respect and sensitivity to hearing their stories developed trusting relationships and yielded some very rich data from bereavement stories, that some participants stated had not previously been shared with anyone. The interview process developed and changed as the researcher gained confidence in the process. In the first interviews the participants shared their stories with very little comment or prompt questions

asked whereas in the later interviews the researcher asked some questions seeking clarification and gaining additional information which was helpful in identifying the ages and modes of death of the deceased.

'The research interview is an inter-view where knowledge is constructed in the inter-action between the interviewer and interviewee' (Kvale 2007:1).

Kvale's play on words provides a good analogy of the qualitative research interview, suggesting that the interview provides an insight, or inside view of the participants' social world and that knowledge is constructed through the interaction between the interviewer and interviewee, thus the purpose of the qualitative interview is to construct knowledge through interaction. This interactional approach differs from the positivist interview method whereby the purpose of the interview is to be a data collection tool (Kvale 2007). Alvesson (2003) offers three perspectives of the interview, firstly concurring with the view of the interview as a tool, suggesting interviews are purely an information gathering exercise in which data is collected without context and the interviewer remains neutral. Secondly he proposes a romanticist view of the interview as a human encounter, a participatory interaction between interviewer and interviewee, and finally the localist view which places the interview in a social context. The romanticist and localist views are aligned with qualitative interviewing focusing on the interaction with interview participants to gain understanding of their experiences and social world. Thus Interviews in qualitative research are more than just a tool, or method of data collection, they are an integral part of the research process with the emotional interaction and involvement developed between researcher and participant influential in shaping the outcomes of the research (Bold, 2012; Ritchie et al 2014).

Ezzy (2010:163) also argues that emotions are central to the interview process, discussing the *'emotionally embodied performance'* as vital to a successful interview process. Dickson-Swift et al (2008) reiterate this view stressing the importance of an emotional commitment between the interviewer and participants, particularly in sensitive interviews. The emotional framing of the interview process needs to consider the impact of emotion on the behaviours

of the participants (Valentine, 2007). This is particularly relevant to this study, with the sensitive and at times traumatic nature of the bereavement stories, which inevitably led to some tearful responses and poignant silences during the narratives. However these emotional responses and associated behaviours provided emphasis to the stories told, becoming an important part of the data analysis (Clandinin, 2013).

In this type of emotional interview, an unstructured, life experience interview, or narrative inquiry which has a conversational basis, and is defined as *'naturally occurring talk'* (Silverman, 2001:16), consideration must be given to interaction between interviewer and participant (Hannabas, 1996; Denzin & Lincoln, 1998, Clandinin, 2013). Although the focus is on the participant story teller rather than the interviewer, as discussed in the earlier section on narrative inquiry, the interviewer needs to have the skills to be an attentive listener, judging when to probe and develop the interviewee responses and when doing this might interrupt or change the direction of the narrative or invade the privacy of the respondent (Qu & DuMay, 2001; Valentine, 2007). However failure to probe or extend the discussion can also lead to missed opportunities to clarify or extend information shared. In the first three interviews of this study researcher intervention and questioning was minimal, a communicative dialogue confirming and acknowledging the participants' comments, using silence and echoing probes rather than direct questioning (Price 2001).This was a deliberate choice to ensure that the interview participants had control of the information shared and to develop trust and a comfortable relationship between interviewer and interviewee. This relationship was established and some very rich data gathered. Nonetheless there were missed opportunities where additional information could have been gained by additional questions or probing, but this may have been a step too far into the privacy of the individuals taking part. Allowing the participants to tell their stories freely rather than through structured questioning, the narratives provided some rich data which reinforced the initial themes identified in the focus groups providing the emergent findings of the study.

The role and relationship of the researcher

'*The establishment of trustful relationships depends on the quality of the interpersonal engagement between the researcher and the researched'* (Lee 1993)

Establishing trusting relationships was one of the main challenges of this study with the researcher and participants coming from different cultural backgrounds. Being from the mainstream population the researcher is an outsider to the very close knit communities that Gypsies and Travellers live in and their experiences with the mainstream population are often negative involving prejudice and discrimination, thus making them wary of outside intervention (Okely1983; Quarmby, 2012; Powell, 2013). As the qualitative research process produces data that is socially constructed as a result of the interaction between the researcher and participants the characteristics of the researcher are significant to how the interview context is developed and the narrative constructed. Lincoln & Guba (1985: 155) describe the researcher as a *'human instrument'* in the research, the benefits include being able to be more responsive to sensitive issues and to interpret responses However this is only possible with the establishment of trust and respect between the researcher and participants.

Relationship building was facilitated by the support organisations. These are operated by and for Gypsy and Travellers and essentially acted as the community's gatekeeper therefore providing some assurance that the researcher was trustworthy.

The development of trust was an interesting process, and one which at times led me to question my own ethical stance in pursuing the study as gaining access to participants required a process of continual and repetitive phone calls when trying to set up focus groups and interviews. There was a strong commitment given to taking part in the study made at the initial contact, however it then took approximately six months to actually meet face to face following a succession of calls which at times felt as though I was chasing individuals to participate, leading me to question my position ethically in pursuing these participants.

However the divide between cultural mismatch of understanding and trust building became apparent when viewing the development of trust during one of the narrative interviews:

"*With Travellers if you offer them something the Travellers are so suspicious they say no we don't need it, but if they went back a second time they build a bit of trust but its giving up at the first hurdle and the travelling community will refuse at the first hurdle. It's what they are, it's what they've been reared to do they don't let strangers in straight away they have to know who you are and what you are about even if you come and say I want to do this they'll say no but then they'll think about it and if you come back a second time they'll say yes come in but nobody really gives them a second chance so I don't think that people should give up so quickly on Travellers" (*narrative B)

This helped to develop an understanding that the process of calling several times was about proving that the researcher was trustworthy and sufficiently interested to persevere and establish a relationship prior to meeting face to face. The development of trust continued with the focus groups where it was interesting to observe that during introductions the participants were initially wary. However once they had established that the researcher was not a nurse, psychiatrist or counsellor their attitudes and body language became more relaxed and open. Not being a health professional or a counsellor was a significant factor in the development of trust and a positive and open relationship with the Gypsies and Travellers taking part. In additional the researcher was honest and open acknowledging limited knowledge and understanding of Gypsy and Traveller culture but demonstrating an interest to learn more about their heritage. This and the fact that the researcher was not a health professional, but was in fact an early years specialist interested in children and families was an important factor in establishing a relationship that was trusting and respectful. Furthermore, being a female researcher interviewing women, with a professional interest in children and family, (also of fundamental importance to Gypsy and Traveller identity) helped to establish some commonality and reduce the divide in cultural backgrounds. Oakley (1981, 2005) highlights the benefits of women interviewing women

suggesting that female cultural affinity develops closer research relationships; certainly in this study the identification of some shared interests and values was influential in establishing a sound research relationship.

The success of this relationship is demonstrated in the stories told, with many of the participants sharing experiences which in some cases related to the loss of children many years earlier that they had not previously spoken about to anyone else. Whilst these were intensely personal and emotive experiences I felt privileged to have been trusted enough to hear these stories. The following comment confirms that trust was established.

'*I wouldn't talk to a stranger, it would have to be someone I could trust, if, I saw you now I could tell you more things because I know you. You have to have trust and confidence in whomever it is* '(focus group participant).

Whilst it is clear that trust was established, the balance of power and relationship of equality between the researcher and the participants is less easy to define. Was the openness to share bereavement experiences due to the relationship established? Or was it because an outsider gave permission to tell these stories in a forum where there was no potential impact on family or community, or perhaps a combination of both?

These examples illustrate the fundamental importance of building relationships. As Blackburn et al (2010) advocate '*start with the person'* and the research will follow. Certainly for this study the development of relationships was essential to establishing trust and credibility with the Gypsy and Traveller communities so that they would share their experiences. This meant recognising the emotive aspects of the research subject; the participants were not research subjects but individuals who had experienced sometimes traumatic but always distressing loss of close family members. Thus the focus for this study is the person and the life story they have to tell. Therefore unlike a structured interview approach the participant not the researcher controls the process with the role of the participant as the story teller and the role of the researcher as the listener. Nonetheless the

listener must be trusted and respected enough to be told the stories (Holloway & Jefferson, 2000; Liamputtong, 2007).

Researcher reflexivity

The participatory role of the researcher in qualitative research studies is common, as is the debate surrounding the neutrality and potential bias created through the interaction and participation of the researcher on the outcomes of the study. Social research increasingly uses the inclusion of researcher reflexivity to overcome any such bias and reflexivity is increasing seen as essential in validating and minimising the subjectivity of the study (Denzin & Lincoln; 1998, 2013; Silverman, 2006).

It is the reflexivity of human nature that forms personal perspectives and experiences that influence the social worlds of individuals and societies and that form the basis of social research (Dressman, 2008). For successful social research a reflexive approach must be taken, recognising the impact that the researcher's own values and beliefs, or '*owning ones perspective'* may have on the research outcomes (Elliot 1999:220). In this study I needed to understand the cultural beliefs and values surrounding death in Gypsy and Traveller communities, but also those relating to the importance of family, gender roles and the place of women in Gypsy and Traveller families and society. Thus it is essential to understand the contexts of the participants' lives to be able to accurately interpret participant narratives (Ritchie & Lewis, 2003; Wells, 2011). This requires both reflexivity and theoretical sensitivity, that is, the ability to demonstrate sensitivity and understanding of the concepts formed from the research narratives based on both personal and professional experiences (Clandinin, 2013; Strauss & Corbin, 1990).

In this study as the researcher my background is significantly different from that of the participants; however, there are also some similarities in that we both have experiences of death and the loss of family members, albeit that they are in very different circumstances. Reflecting on the narrative stories of the loss of family members I needed to consider why

some of the stories had a greater impact on me emotionally than others: supervision from CBUK was effective in supporting my reflexivity and identifying the reasons for this. This is important when considering the analysis of the stories to be able to remain objective to all of the stories told. Furthermore Woodthorpe (2011:100) suggests that it is difficult to maintain a critical distance by a researcher studying bereavement based research as '*we are all participants in mortality, not just observers'* and as such unable to be completely detached. This leads to the position of the researcher as both an '*insider* and an *'outsider'* in the research process (Okely, 2012), I am an insider to experiences of loss and grief but I am an outsider to the Gypsy and Traveller community and I need to be aware of how my own culture and experience is situated in the knowledge gained to provide a balanced and objective interpretation of the stories told.

The role and position of the researcher

Qualitative research is socially constructed and narratives co-constructed, therefore the social interaction between the researcher and participant during the interview process will have some influence on the outcome of the narrative (Andrews et al 2013). Robert & Shenhav (2014) suggest that the role of the researcher in narrative inquiry is as a facilitator, providing the conditions for the research participant to share their story uninterrupted. In this study the researcher's position was that of facilitator, providing a respectful space for the narrators, the deceased and their stories.

The facilitative position taken in this study was fundamental to meeting the aims of the study, the sensitivity of the research subject and to establishing relationships with the Gypsy/Traveller participants. A facilitative position enabled the participants to control the dialogue and for their voices to be heard, they often remain hidden in mainstream consciousness (Ryder, Cemlyn & Acton, 2014). Equalising the power balance towards the participants was an important aspect of developing trusting relationships between the participants and researcher.

Dickenson-Swift et al (2007) discuss researcher's sharing experiences as a strategy to develop the research relationship, I chose not to do this instead maintaining '*empathic distance'* (Valentine, 2008:170). In contrast to the complex, multiple and intergenerational bereavement experiences of the Gypsy and Traveller participants my own bereavement experiences seemed in many ways incomparable but nonetheless significant.

During initial analysis of the narratives I had ignored my own contributions to the narratives. My role was to listen, remain unobtrusive and not influence the narratives, so my contributions seemed unimportant. Valentine (2008) discusses how she had '*edited out'* her own responses to bereavement narratives in her research study, I had done the same, ignored my own responses and contributions to the narratives I had heard, focusing instead on identifying common themes in the bereavement stories. Having chosen a thematic rather than linguistic approach to analysing the data I did not consider my contributions valuable nor did I initially consider how my responses may have shaped narratives. Reflecting on this and revisiting the transcripts confirmed my interactions in the narratives as a facilitator, using active listening and paraphrasing to confirm and clarify the meaning of stories told. Thus my contributions provided a supportive, encouraging and safe environment within which the participants shared their stories.

As I listened to the bereavement experiences the deceased became a strong presence in the stories, gaining a sense of who they were and the relationships between the deceased and storyteller. Very strong continuing bonds and respect for the deceased was evident throughout all of the narratives. Valentine (2008) suggests that narrators take great care in choice of vocabulary used to represent the dead. In this study many of the participants referred to deceased family members in the present tense reinforcing their strong continuing bonds with the deceased, as in this example, '*I have got a 29yr old boy who died when he was two weeks* old'(narrative F). On a number of occasions the use of the first person left me unprepared for what was to follow, as in the example above I heard *'I have got a 29yr old boy'* but was not prepared for what followed. Dickson Swift et al (2008a:136) highlight the

need to consider the ethical protection of researcher as well as participants particularly when researching sensitive subjects, suggesting that '*in providing space for participants to tell their stories researcher's may be taken to places for which they were not prepared'.* Whilst the open participant led narrative approach may have increased my vulnerability as a researcher I had only to listen not live with the losses as the storytellers do. Nonetheless supervision was pivotal to helping me manage my own feelings towards the stories told and to objectively analysing and sharing the stories in a meaningful and respectful way.

Sensitive research

Sensitive research has two strands, the sensitivity of the subject matter; this is often intensely personal, intruding into the *'private space'* of individuals, whilst the second strand refers to the vulnerability of the participants who are often socially vulnerable, marginalised or hidden populations (Liamputtong, 2007:2).

Although any topic has the potential to be sensitive, the degree of sensitivity attributed to a subject is often socially constructed (Lee1993). Certainly bereavement research is influenced by the socio-cultural environments in which it takes place (Straudt & Block, 2012). Western society has seen the social constructs of bereavement and grief shift from being underpinned by religion, to sequestration and medicalisation moving death from the public to private domain (Howarth,2007; Walter, 2008;). Moreover changing theoretical perspectives continue to influence how bereavement and grief are managed. Medical and psycho-social approaches introduced a new focus to grief and bereavement by looking at the impact of death and dying in relation to mental health and wellbeing of the bereaved (Worden, 2009; Parkes & Prigerson, 2010). It is within this framework that the focus of this study is positioned. However the social context of death in the Gypsy and Traveller community differs from that of mainstream society as it remains underpinned by cultural traditions and religious

belief keeping death central to community life (Okely,1983; Williams, 2003). Consequently the sensitivities of this research relate to crossing societal and cultural boundaries.

Sieber & Stanley (1988:49) further define sensitive research as studies in which there are '*potential consequences or implications for the participants'.* Bereavement research falls into this category as it has the potential to cause emotional distress to the participants by requiring them to recall bereavement experiences, thus raising further debate about the ethical stance of bereavement based research and the need to ensure the protection of participants from emotional harm (BERA, 2004, McCosker et al, 2001). Consideration needs to be given to the societal and personal bias attached to defining sensitivity and vulnerability in research and assumptions made about how participants may react (Cook, 1995). Whilst there is no doubt that participants in sensitive research may be emotionally vulnerable, Parkes (1995) asserts that they remain competent in decision making and aware that participation in bereavement based research may entail emotional and potentially distressing discussions.

Regardless of this risk Stroebe, Stroebe and Schut (2003), Dyregrov (2004) and Briller et al (2007) found that participation in bereavement based research could be therapeutic rather than harmful, as bereaved individuals typically report the need for opportunities to tell their stories outside of their own family and social environment, (see further in the ethics section of this chapter). Opportunities to share bereavement stories as a positive and therapeutic experience are endorsed by Niemeyer's (2011) meaning reconstruction theory in which narrative storytelling is used as a meaning making process, contextualising the loss and facilitating the process of grief.

Undoubtedly there are both potential risks but also benefits to sensitive research, Lee (1993) proposes that rather than avoiding sensitive subjects, researchers should find ways to resolve or minimise the potential harm to the participants. Therefore, within this research, consideration needed to be given not only to bereavement but also to the distinct cultural

traditions and heritage of Gypsies and Travellers which is often at odds with mainstream society (Acton, 1997; Ryder, Cemlyn & Acton, 2014) and that of the researcher, who being from the majority population is an outsider to the Gypsy and Traveller community. The juxtaposition of the differing cultural backgrounds of the researcher and participants in relation to the wider beliefs and experiences of death and loss was fundamental to the selection of a narrative approach as it provides a more empowering approach for participants to share their life stories (Clandinin & Connolly, 2000).

The research is designed to tell the stories of bereavement experiences within Gypsy and Traveller families and to consider if the close-knit family and community bereavement behaviours offers effective support for managing the processes of loss or potentially exacerbates the risk of long-term complicated grief, or if in fact there is a need for external bereavement support services.

In view of the potentially differing perspectives of the researcher and participants it is important to consider the concepts of '*need'* and *'support'* as the interpretation of these terms may be perceived differently by individual participants and researcher, who has access to practical and theoretical models which the participants may not have. The researcher's' perspective is drawn from the interpretation of these words, as a requirement for help. The participant understanding of need and support will vary based on individual resilience and experiences across all areas of their lives (DH 2011), hence there may be a need for some individuals but not others and support could come in various guises either internally from family or the community or externally from Child Bereavement UK or a similar support service. Therefore as an outsider looking into the Gypsy and Traveller community the researcher's' perception and interpretation may be very different from those of the bereaved participants. Hence this study questions whether the close cognate family and community structure provides the necessary support following bereavement or if in fact it becomes a barrier attributing to and complicating the process of grief (Worden, 2003; Parkes & Priggerson, 2010). Consideration has also been given to the limited research available

which suggests that multiple bereavements are the underlying cause of poor health and risk taking behaviours (Parry et al, 2004 and Cemlyn et al, 2009), potentially identifying a need for support interventions. Thus as an outsider the researcher's point of view may differ from that of bereaved individual who may offer a very different perspective of the 'need for support.' Indeed the stoic nature of Gypsies and Travellers, particularly women, may place the threshold of need so high that they may not identify personal need for support just accept as their lot in life (Greenfields 2008; Hodgins et al, 2006; Richardson et al, 2007; Smith & Rushton, 2013; Van Cleemput, 2010).

Whilst some of the bereavement issues identified may not be dissimilar to those of the wider population, the prevalence of bereavement and the lifestyles of Gypsies and Travellers are significantly different from the mainstream society (Cemlyn et al, 2009).So to establish the differing needs of the Gypsy and Traveller community the research focuses on their narrative stories rather than a comparative study with the wider majority population. A comparative study may have highlighted the similarities and differences between the bereavement experiences of the majority population and Gypsies and Travellers, however the aims of this study were specifically to explore the bereavement experiences of Gypsies and Travellers. Whilst some comparative elements may highlight differences, using a narrative approach allowed a clear focus just on the lived experiences of the participants.

The methodology chosen enables the participant's voice to be heard, reflects the sensitivity of the research subject and the vulnerability of Gypsies and Travellers as a minority ethnic group (CRE, 2006). Consequently the following factors influenced the choice of methods:

- The sensitivity of bereavement as a research topic (Lee,1993; Liamputtong,2007) coupled with the knowledge that Gypsies and Travellers have significantly higher mortality rates than the mainstream population and an increasing recognition of prolonged and complicated grief from multiple and often traumatic bereavements (Cemlyn et al, 2009; Parry et al, 2004).

- Recognising that recalling bereavement experiences could be either distressing or therapeutic for the participants support strategies were in place, these included informal support with familiar people provided through the advisory organisations and contact details for local and national bereavement support services. Despite having a range a support strategies in place evidence suggests that typically these may not be taken up by the participants as Gypsies and Travellers have poor access to and a reluctance to use mainstream services, often being the recipients of prejudiced experiences from interactions with mainstream service providers (Hodgins et al, 2006; Mathews, 2008; Rushton & Smith, 2013; Van –Cleemput, 2007).

- Consideration of the difference in the background of the researcher as a member of the mainstream population and an outsider to the Gypsy and Traveller community and the importance of establishing an open and trustful relationship in which the participants would share their stories.

- The researcher's ethical perspective and belief in the importance of allowing the participants to retain ownership of their stories and control what information they shared rather than using a formal interview approach with questions that are potentially distressing for the participants.

- Supervision from Child Bereavement UK undertaken by the researcher to support a reflexive approach enabling her to recognise the impact of her own personal emotional responses and experiences of loss and how these were influenced by hearing the stories of others would impact on her feelings. Lee (1993:1) considers the impact of sensitive research on the researcher as often having *'potential effects on the personal life of the researcher'.* This helped to protect the researcher and to ensure that congruent and beneficent practice was demonstrated throughout the study (BACP, 2010), helping to maintain an objective approach to the stories told and to support the research participants.

Ethics

The ethical considerations for this study are significant given the sensitive nature of the study and the vulnerability of the participant group of Gypsies and Travellers. Ethically the study needed to balance the benefits of the study with the impact on the participants considering the rights and wellbeing of each individual (BERA, 2004; BACP, 2010). Therefore the main consideration for this study was protection of the participants from emotional harm given that the focus of the research has potential to cause distress with participants reflecting on life experiences of bereavement and loss (Allmark et al, 2009; Stroebe, Stroebe & Schut, 2003).

There are an increasing number of research studies looking at the impact of bereavement, Beck and Konnert (2007) have categorised studies into two areas, theoretical studies providing advice and guidelines for ethical congruence, such as Cook(1995) and Parkes (1995) and empirical studies investigating the responses of participants of bereavement research, including Dyregrov (2004).These studies provide balanced considerations for both the ethical dilemmas relating to bereavement research but also evidence to support the benefits of participation in such research. For example Parkes (1995) proposes that it is unethical to develop bereavement based services without prior research to ensure that any service provision is appropriate, but acknowledges the considerable ethical issues when undertaking research with bereaved individuals. This is a pertinent point for this study as Gypsies and Travellers are vulnerable with complex lifestyles and health issues, which in some instances may be related to prolonged and complicated grief (Cemlyn et al, 2009), thus making them potentially vulnerable research participants. However, as an ethnic group with a distinct cultural heritage very different from the mainstream population it is essential to understand the traditions, beliefs and grief processes of these communities to be able to establish appropriate support strategies, which can only be identified though research.

There is a juxtaposition of views based in societal norms and values surrounding death, with ambivalent attitudes towards death within society influencing the ethical perceptions of bereavement research. This suggests that personal unease and discomfort can create bias and barriers to bereavement based research, with the perceived need for the *'ethical protection of vulnerable groups'* making assumptions that bereavement based research will be harmful (Cook, 1995). Conversely research evidence by Dyregrov (2004) suggests otherwise, that research participation can be beneficial both to the individual and others. Nonetheless it is essential that bereavement research balances the personal impact to individual participants and any social benefits of the research' Respondent evaluation of research by Dyregrov (2004) investigating the participation of bereaved parents in research concluded that the most positive aspect was being able to tell their story and whilst this was painful it was also beneficial to the bereavement process. Stroebe, Stroebe and Schut's (2003) and Parkes (2006) findings were similar with participation in bereavement research being helpful in coming to terms with loss.

Given that Cemlyn et al (2009) identified health issues that are reflective of complicated and prolonged grief alongside the circumstances surrounding premature deaths within the Gypsy and Traveller communities, Dyregrov's (2004) study suggests that research participation can be therapeutic and beneficial rather than harmful, concurring with the earlier findings of Parkes (1995 :175) suggesting that '*expressing grief can be therapeutic'*. Further endorsement is found in a study by Briller et al (2007) who established that using focus groups and interviews allowed bereaved parents to contribute and share their stories in a way that they were unable to do in a wider social environment. This point of view was validated by a number of participants in this study who shared information that they had previously not shared with family either to protect family members or because of cultural expectations of roles and responsibilities. Nonetheless whilst research evidence supports the benefits of participation in bereavement research, this is an extremely sensitive area of study and the foremost consideration must to be given to the emotional needs of the

respondents. Parkes (1995) proposes that participants taking part in bereavement related research expect the experience to be distressing, thus suggesting that participants, although vulnerable are competent in their decision making and are fully aware of the implications of taking part. Beck and Konnert (2007) concur with the view that bereaved individuals remain competent to consent to research participation and identified benefits for both participants and for the education of others. This view suggests both intrinsic and extrinsic motivators for participation in research relating to bereavement. This study supports this stance; intrinsically the study provided an opportunity to speak of loss not previously available and extrinsically the opportunity to acknowledge the need for the provision of culturally appropriate bereavement support.

Involvement in this kind of study can provide the opportunity for the voices of under presented groups to be heard (Liamputtong, 2007). Certainly for the Gypsy and Traveller women in this study, participation gives a voice to the women of a marginalised community, which due to gender role expectations and protective strategies of close family relationships, bereavement and the feelings associated with loss would not normally be openly shared.

Concern for the participants was reflected in the choice of method. Unlike a structured interview the narrative, or open interview approach is less intrusive thus ensuring that control will be with the respondent rather than the researcher giving the participants autonomy and control of the information shared relating to their life stories. As a result there was a need to be aware of and empathic to supporting the needs of the participants. Reassurance was provided to ensure that respondents were aware that personal wellbeing would take priority over the research outcomes during focus groups and the narrative interview process. Reflecting on the loss of a close family member generated some very emotive narrative and it was essential that participants were secure in their relationship with the researcher to be able to withdraw from the research if their stories became too difficult to tell. Whilst there were some tearful and reflective silences during some of the interviews no one withdrew from the study.

A short debrief followed each interview to provide closure of the session and ensure that the emotional health and wellbeing of participants was maintained. Participants were reminded of support available from the advisory organisations and of additional specific bereavement support services. However whilst the need for support was identified during the research there is no guarantee that individual respondents will accept support services offered given that experience shows that Gypsies and Travellers are often reluctant to access external support services. Van Cleemput (2000) proposes that the mobile lifestyle and discrimination experienced by Gypsies and Travellers when accessing health services makes them reluctant to use external services which is all that is currently available. Smith and Rushton's (2013) more recent findings confirm that there has been little change in access and use of universal service provision with Gypsies and Travellers continuing to self-diagnose and self-medicate rather than use mainstream services.

Ethical research with children, vulnerability versus competence

The ethics of researching with children are embedded in the social constructs of childhood. The concept of childhood in Western society has evolved from a historic perspective where children were seen as imperfect or incomplete adults, to the emergence of childhood as a distinct life stage where children are socialised towards adulthood (Aries, 1962; Cunningham, 2005; James & James, 2004; Leonard, 2016). However childhood, as many other social norms, is only representative of the societal beliefs of any given time. '*It is in other words what members of particular societies at particular times and in particular places say it is'* (Wagg, 1992:10).Thus childhood in mainstream Western society has been underpinned by a deficit developmental model focused on what children cannot yet do (Graham et al, 2015a; James & James, 2004; Leonard, 2016). As a result children's lives are determined by adult actions and the concepts of childhood defined through adult eyes (Cunningham, 2006). This attitude of adultism or the ideological perception that adults are more competent and better informed to be able to act in the best interests of children, makes assumptions about the competence of children to make their own decisions. The stance of

adultism is based on the premise that children are vulnerable, dependent and in need of protection (Desai, 2010).

Undoubtedly childhood is a period of dependency and reliance on adults; however since the introduction of the United Nations Convention on the Rights of the Child (UNCRC) and ratification of this in the UK in 1991, there has been a shift away from the deficit approach of childhood to the emergence of a rights based stance. Whilst the UNCRC promotes children's rights to protection article twelve states that children who are capable, considering their age and maturity, have the right to form and express their own views on matters that affect them (UNICEF, 1989). This creates juxtapositions that challenge adults to both uphold children's right to protection but also to recognise and promote children's right to participation and a voice. This approach recognises and promotes children as social actors and although they lack social power they participate in society from birth, discovering their voice in infancy to influence events and make their needs heard (Hart, 1992; Harcourt et al, 2011). Nonetheless as increasingly a rights based approach becomes the Western mainstream societal norm, children's agency and voice remains somewhat rhetorical with some naivety in adult advocates, Although there is increasing recognition of children as competent decision makers' children do not have the same decision making powers as adults so in many instances the attitudes of adultism remain prominent. Consequently how adults view children, either as vulnerable or competent '*experts in their own lives'(Clark & Moss, 2005:5)* is fundamental to the ethical considerations of conducting research with children.

Ethical research with children

The recognition of children's rights, competence and agency has had a significant influence on approaches to research with children, moving from research '*on*' to research '*with*' children (Roberts-Holmes, 2011; Hammesley,2015). A rights based approach now underpins much of the research involving children, influencing the ethical stance by recognising children's rights to both participation and protection (UNICEF, 1989). Children's rights to

both participation and protection are also underpinned by the Children Acts of 1989 and 2004. Thus there has been move away from children being considered in need of protection, amongst the most vulnerable and at risk as research participants (Liamputtong, 2007), to recognising children's competencies and empowering them. However this is not without difficulties, Alderson and Morrow (2011) suggest that the challenges are in enabling the voice of the child to be heard without exploitation and protecting children without silencing or excluding them.

The ethical research involving children project (ERIC) has developed a framework for research with children which aims to uphold the dignity, rights and well-being of children as research participants (Graham et al,2013). The framework is formulated around the key concepts of reflexivity, rights and relationships.

Reflexivity refers to the self-awareness of the researcher, considering personal childhood experiences and adult engagement with children (Graham et al, 2015b). In this study this required the recognition of different cultural experiences and behavioural expectations of Gypsy and Traveller children. For example although highly protected within their communities, the behavioural freedom and involvement in adult life experiences is greater than that of mainstream children and of the researcher's own experience. This meant recognising and responding to the nuanced behaviours of the children during the workshops, the sibling hierarchy and responsibilities of older children for younger siblings. Also recognising and respecting the children's competence and self-regulation when the younger children removed themselves from the main group to their own secure place and space under a large table, outside of, but within sight of the main group for one activity. The need for reflexivity and flexibility was evident during the workshop as some of the younger children opted in and out of the different activities that took place. This was a good example of ethics in practice and the flexibility of the process that allowed each child ongoing participatory choice throughout the research process. As a result ethical reflexivity ensured that children's participation and the workshop outcomes reflected their choices and voices, ensuring that

children's rights and well-being were the foremost consideration during the workshop. Moreover this upheld the second strand of the ethical framework of respecting children's rights.

The third strand of the framework is relationships. Research with children inevitably involves multiple relationships and power disparities between adults and children. Power differentials between adults and children can result from differing frames of reference, influenced by age, experience and culture; these in turn influence concepts of competence or vulnerability and need for protection. In addition children's responses to consent or assent may be influenced by adult power relations whereby children consent or comply as a result of wanting to either please or obey the adult (Morrow & Boyden2014). It is the power differences between adults and children that lead to many of the ethical complexities of research with children, as discussed in the following section that considers informed consent (Graham et al 2015a, 2015b).

Informed consent

One of the core principles of ethical research is that of informed consent. Ensuring that research participants are fully informed and aware of what involvement in a research project entails and consent without coercion are fundamental to ethical research practice. Whilst this is relatively straightforward with most adult research participants there is much debate surrounding the capacity of children to fully understand what is involved and be able to give informed consent.

UK law also lacks clarity as there is no specific requirement for adult consent for children's participation in research (Boddy, 2014). Nonetheless in the UK children under the age of eighteen are legally minors and parental responsibility for protection is situated in the Children Act 1989 (HM. Government, 2016). Further complexities can be found in legal frameworks such as the Fraser Guidelines (based on the Gillick ruling in 1985 which challenged the need for parental consent for medical treatment in children under sixteen).

The outcome of which ruled that in law parental consent for medical treatment is not required where children are deemed competent in giving informed consent, and that children's competence to consent should be judged on an individual basis (Boddy, 2014; Lambert & Glacken, 2011). However this stance is complicated, UK legislation upholds children's rights to form and express their own views through the principles of the UNCRC which are embedded within the Children Act 1989 and 2004. However there is a lack of clarity when it comes to children's capacity to give informed consent, although there is no specific requirement for adult consent to children's participation inevitably as adults hold the balance of power parental consent remains paramount, more often than not children assent rather than being given the opportunity to fully consent (Boddy, 2014; Nairn & Clarke, 2012). Assent assumes children's agreement following parental consent and is commonly used in the absence of recognising children as competent decision makers (Hammersley, 2015; Roberts-Holmes, 2011).

Good practice includes obtaining consent from both parents and children, balancing both parental responsibility and protection for the child and the child's right to autonomy and independent decision making (Graham et al, 2015b). Moreover parental consent and involvement may also be beneficial by supporting the child's decision making process. Thus obtaining consent when children are research participants can involve multiple relationships and several layers of permissions including gatekeepers, parents and children themselves (Graham et al, 2013; Shaw et al, 2011). The National Children's Bureau offer some clarification between parental and children's consent, suggesting that parental consent gives permission for the researcher to ask the child to participate whereas the child consents to actually take part (Shaw et al, 2011). Although informed consent is gained prior to the start of the research it is particularly important that there is flexibility throughout the process so that children can re-negotiate their participation or withdraw at any point during the research.

Both parental consent and that of the children was obtained prior to the start of the workshop and the importance of flexible re-negotiation was evident throughout the children's

workshop, particularly for the younger children who opted in and out of the different activities. The information given to the children explained that the workshop would involve stories about someone who had died and talking about how the story characters would feel when someone they loved died. In addition they would be asked to do some drawings and be included in photographs taken during the workshop which would then be used to produce a book for Gypsy/Traveller children to help them understand loss and death. How the project was explained to the children was important to ensure that they fully understood what they were being asked to participate in and were able to give informed consent.

Ethical considerations for the children's workshop

The discussion thus far has highlighted the complexities of ethical research with children much of which has focused on children's rights to both protection and participation and their competence as research participants. In addition the research topic also needs consideration; the main ethical discussion highlights the potential sensitivities of bereavement as a research subject. How to manage the sensitivities of discussing bereavement with children was fundamental to the research design and method when extending this study to include children, as was the recognition that the participants would have differing developmental understanding and experiences of death and loss. To ensure protection of children from harm the research method chosen used stories to provide a safe framework whereby the children were able to discuss complex and potentially distressing experiences such as death by projecting their thoughts and feeling through the story characters rather than their own experiences (Gersie, 1991).

Ethics in practice

In practical terms the ethical considerations for the study related to ensuring that:

- Participants had not have been bereaved within six months prior to taking part in the study. The rationale for this was to prevent any potential distress for recently bereaved individuals who may still be acutely vulnerable. Although there is no set timescale for how

long grief should last, normal grief responses usually take between six months and two years for the bereaved return to normative, albeit adjusted life patterns (National Cancer Institute, 2013). Therefore six months was considered the minimum timescale for participation in this study.

- The wellbeing of the participants remained paramount throughout the study, and participants were reassured throughout the process that they were able to withdraw if their stories became too difficult to share.

- The advisory group organisations provided a link between the researcher and the Gypsies and Travellers taking part in the research, acting as gatekeepers and providing additional support for research participants if necessary.

- Informed consent was gained prior to participation in the study. Written information and consent forms (see appendix 5 and 6) were provided and these were reinforced with verbal explanations as not all participants were literate. The support organisations acted as impartial readers and signatory witnesses for participants with low literacy levels, thus ensuring that all participants had equal access to information to allow informed consent to be made.

- Privacy and anonymity have been maintained, names and places have not been identified in transcriptions, however given the very personal nature of the life experiences shared they may be identifiable to those close to the participant whilst not to external audiences.

- Audio tapes and transcriptions of the focus groups and individual sessions are held securely on a restricted access file by the researcher.

- The research was carried out following the British Educational Research Association (BERA) principles and guidelines and to the requirements of Buckinghamshire New University's Faculty of Society and Health Research Ethics Committee.

In additional to the above the following were also considered specifically for the Children's workshop:

- The researcher, storyteller and photographer (engaged to provide images used in production of the children's book) all have education backgrounds and hold enhanced disclosure and barring (DBS) checks recognising that they are safe and appropriate adults to work with children.

- The researcher was mindful of the additional need for flexibility and the ongoing negotiation of consent, allowing the children to opt in and out of the workshop activities as they chose.

Analysis

Analysing qualitative research 'retains the complexities, nuances and respect for the uniqueness of the individual as well as recurrent themes' (Ormston et al, 2014).

A qualitative approach to analysis values the richness of data that as the quote above states recognises and respects the uniqueness of the individual, offering 'a *window'* into individual lived experiences and the social worlds of the participants (Andrews, et al, 2103; Clandinin,2013; Robert & Shenhav, 2014). Therefore the analysis of these lived experiences must effectively represent the rich complexities, ambiguities and similarities and differences within the stories told. Moreover in contrast to quantitative analysis '*working with personal narratives is not a search for truth but an acknowledgement of personal experience at that moment in time'* (Bold, 2012:122).

The flexibility of qualitative research means that there are differing analytical approaches available. Spencer et al (2014) suggest two categories of qualitative analysis, substantive and structural. A substantive approach, found in grounded theory or thematic analysis, focuses on the content, context and patterns of meaning found in the data. Whereas a structural approach, found in discourse and some types of narrative analysis has a linguistic focus and is concerned with the interaction and structure of the talk and text. Furthermore

Reissmann (2008) discusses differing analytical styles with specific application to narrative research, suggesting three approaches to narrative analysis. The first, structural analysis focuses on the telling of the story, secondly dialogic analysis, looks at how the story was produced and finally thematic analysis in which the researcher identifies themes or patterns within the story. This study uses a thematic analysis to identify similarities in the stories and bereavement experiences of the participants.

Thematic analysis

Thematic analysis refers to the identification and analysis of recurrent patterns within the data (Braun & Clarke, 2006, 2014; Cresswell, 2013; Ryan & Bernard, 2003). Boyatzis (1998) defines thematic analysis as '*a way of seeing'.* He describes the process of thematic analysis in three stages observing or recognising something important (seeing), coding it (seeing it as something) and then interpreting or applying meaning to it (Boyatzis, 1998: 1).

Thematic analysis is a widely used approach across qualitative research methodologies, particularly suited to social phenomenology (Joffe, 2012; Spencer et al, 2014). Thematic analysis is not aligned to a specific theoretical perspective, giving it a flexible application. However the lack of affiliation to a specific theoretical framework has resulted in criticism that thematic analysis is a generic, simplistic and descriptive approach (Rohleder & Lyons, 2015). Conversely Braun and Clarke (2006) argue that the strength of thematic analysis as an analytical method is in its flexibility and that it is an effective method that can provide rich data analysis. Moreover to establish effective thematic analysis Braun and Clarke (2006) reinforce the importance of clarifying the theoretical framework used when applying thematic analysis to a research study to enable comparative evaluation against similar work to validate the study.

Drawing on Spencer et al's (2014) substantive and structural categories of qualitative analysis similarly thematic analysis can be characterised as inductive, where patterns and themes are drawn from the data itself, or deductive and based on prior theoretical

knowledge (Joffe, 2012; Ryan & Bernard,2003).Bold (2012:129) adds an additional element by including experience as a central tenet to the process of thematic analysis, using the term *'thematic experience analysis'* when referring to thematic analysis within narrative research, highlighting the centrality of the individual lived experience within the analytical process. Bold suggests that thematic experience analysis has two aspects, the identification of themes within the narratives and the relationships between people and the context of the experience. Thus thematic analysis in narrative inquiry uses extracts of narrative to illustrate findings; this maintains the authenticity of the story and storytellers intention and reduces researcher interpretation (Reissmann, 2008).

Furthermore clearly identifying the theoretical framework within which the thematic analysis is situated and whether an inductive or deductive approach is taken explicates the perspective of the study, demonstrating validity and credibility to the study (Braun and Clarke, 2006; Joffe, 2012). This study is situated within a phenomenological framework using an inductive approach to the thematic analysis to identify the familial and cultural relationships influencing the bereavement experiences of Gypsies and Travellers.

Data analysis

The study was analysed using Braun & Clarke (2006:35) six phase model of thematic analysis outlined in table 1 below. Manual data analysis was favoured over the use of data analysis software. The NVIVO programme was piloted but did not offer any advantage over manual data analysis for this study, in fact manual analysis allowed the researcher to become immersed and deeply embedded in the data through reading and re-reading the data.

Table 1: Braun and Clarke model of thematic analysis.

Phase	Description of process
Phase 1: familiarisation with data	Transcribing data, reading and re-reading data, noting initial ideas.
Phase 2: generating initial coding	Coding interesting features of the data in a systematic fashion across the data set, collating data relevant to each code.
Phase 3: searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
Phase 4: reviewing themes	Checking the themes work in relation to coded extracts, generating a thematic map of the analysis.
Phase 5: defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story that the analysis tells; generating clear definitions and names for each theme
Phase 6: producing the report	The final opportunity for analysis, selecting compelling extract examples, the final analysis relating back to the research question and literature.

Phase 1: familiarisation with data

Data analysis in qualitative research is an ongoing and iterative process beginning with collating and familiarisation with the data (Spencer et al, 2014). Familiarisation with the data began with the interactions between the researcher and participants during the focus groups and narrative conversations. Listening to the emotional and sometimes traumatic bereavement experiences left a lasting impression and early familiarity with the data. The transcription of the focus groups and narrative interviews, reading and re-reading the data enabled the researcher to become immersed in the data interpreting, gaining meaning and initial concepts from it (Braun & Clarke, 2006). The more familiar the data became the more depth and nuances were found within it.

Phase 2: generating initial coding

The initial coding process was the most time consuming element of the analysis as all transcripts were carefully read and re-read increasing familiarity with the data and starting to identify key concepts and similarities within and across the dataset. Although a thematic

rather than narrative linguistic analysis is the focus for this study during transcription attention was given to the use of language to attach meaning to the stories. For example tones of voice and word repetition were used to provide emphasis to important aspects of the stories. These significant phrases and patterns were underlined alongside key words and started to form initial concept ideas and emergent themes. Thus the initial coding process used an inductive or '*data driven'* approach identifying the most significant aspects of each story (Braun and Clarke, 2006).

Phase 3: searching for themes

This phase draws together all the concepts and emergent themes identified in phase two, organising the data to provide an initial thematic framework (Spencer et al, 2014). Themes or patterns found within the data are most commonly identified through repetition and the identification of similarities and differences within and across the datasets (Ryan & Bernard, 2003). Following on from the initial coding in phase two repeating patterns and similarities were found across both the focus groups and individual narratives, identifying emergent themes within the data. These included both overarching themes found in all the transcripts and sub-themes noted in some but not all of the data sets. To justify inclusion as a sub-theme, thematic patterns were evident in a minimum of three transcripts.

As an example of this process Table 2 below is a working example of the initial coding process of phase two and the transference into key themes for phase three. Finally a thematic map was drawn to provide an overview and visual representation of the initial themes (see thematic map1).

Table 2: Example of thematic coding of transcript.

	Narrative G, phase 1 transcription & familiarisation	Phase 2: Emerging concepts and theme notes	Phase 3: Key themes
1	Content removed from the electronic copy of this thesis on data protection grounds.		
2			
3		loss of baby, stillbirth at 36 weeks	
4		hospitalisation	Hospitalisation
5		Loss of memory/ blanked out in a state, shock??	Health / maternal health
6			
7		invisible voice, wishes ignored	Invisible voice not heard
8		cultural traditions and behaviours- need to bury baby	cultural traditions & beliefs
9			
10		mainstream policy & procedure	Mainstream service provision
11		overriding personal cultural wishes ,	
12		lack of cultural understanding	Support / lack of appropriate
13		appropriate support	support
14		cultural lifestyle mobility	
15		impact of loss on mental health &	Culture –Mobility
16		relationship	Health
17		domestic violence, violent towards	
18		husband	family relationships
19		divorce unusual	long term impact of loss
20		cultural loss, multiple family loss	grief
21		no other children	health
22		acceptance of loss of children within	Cultural awareness
23		Traveller culture	Children
24		substance misuse as coping strategy	
25		Loss not discussed impact on other	Health
26		family members, grandmother.	Family / cultural traditions
27		anniversary of death /	
28		Impact on other family member, loss	Burial place & anniversary of
29		not discussed.	death
		Not talking protecting others	Cultural practice / tradition

Phase 4: Reviewing themes

This phase involves a review of the initial analysis and coding, re-reading all of the transcripts. At this stage themes should become meaningfully coherent and distinct (Braun and Clarke, 2006). This phase involved reviewing thematic map one and reorganising and reducing the number of themes and collating them to produce thematic map two. This resulted in the two overarching themes being socio-cultural and family, with sub-themes of cultural characteristics and death ritual and beliefs under the socio-cultural heading and family functioning and children as sub themes under the main theme of family, (see thematic map 2).

These themes met the aim of the study which is to gain an understanding of the cultural norms and community practices influencing the bereavement experiences of Gypsies and Travellers. However, the close familial and kinship relationships and overriding cultural influences resulted in a blurring of boundaries of the two key theme headings, socio-cultural and family with some of the subthemes overlapping both categories. The cultural context of being a Gypsy/ Traveller was so deeply embedded in both the focus group and individual narratives that the overriding themes coming from the data were culturally focused with individual bereavement experiences becoming obscured. Finding and focusing on the individual required reframing the themes around factors affecting individual bereavement experiences. This was established using the bereavement support model from Child Bereavement UK (CBUK) (see figure 6 on page 144), adapted from several sources including Bowen (1978) and Asaro & Clements (2005),

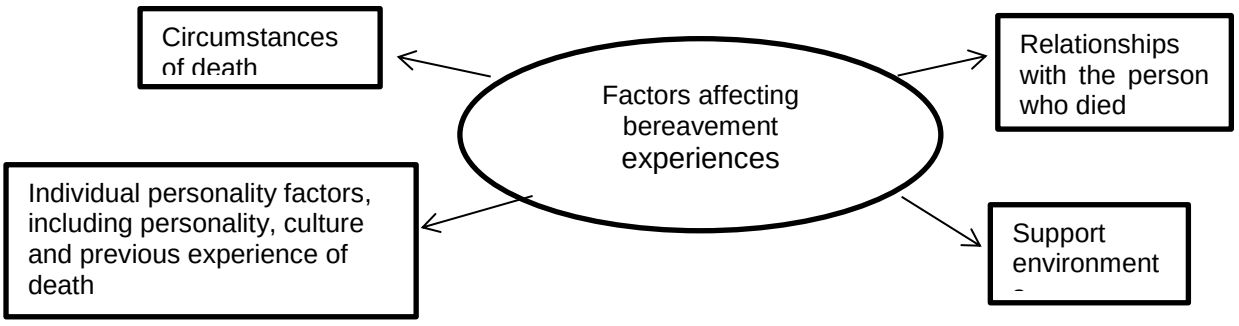


Figure 2: CBUK bereavement support model

Applying the themes identified in thematic map two to this model was a useful exercise in the process of ascertaining how and where each of the themes fit and influence individual bereavement experiences. Using this model added further confirmation that the individual experiences of Gypsies and Travellers are inseparably entwined and underpinned by their strong cultural behaviours and practices. The CBUK model highlights culture as an individual factor whereas the research findings suggest that for Gypsies and Travellers culture is all encompassing, as illustrated in thematic map four on page 145. Moreover by highlighting how embedded individual bereavement experiences are within the close family kinship and community relationships and strong socio-cultural mores, it became evident that '*being a Gypsy/Traveller'* underpins and strongly influences individual bereavement experiences. Similarly the notion of support, albeit often in the form of protective behaviours, was also embedded in and drawn together from all of the subthemes rather than being a separate thematic element as in the CBUK model.

These two factors established that the CBUK model did not fit the data themes as well as anticipated. This enabled the focus of the findings to be moved back to factors affecting individual bereavement experiences set within a cultural framework and the development of the final thematic framework in thematic map four. This shows the cultural context of being a Gypsy/Traveller as an overarching theme that envelops and underpins bereavement behaviours with the key themes drawing together to contextualise how individual bereavement experiences are supported.

Phase 5: defining and naming themes

Thematic maps two, three and four show the process of refining the themes to three key themes titled socio-cultural characteristics, family and support. The socio-cultural characteristics theme has the sub themes of personality characteristics, patterns of death

and death ritual and belief. The key theme of family has subthemes of relationships and children. These are drawn together by the third overarching theme of support.

Socio-cultural characteristics: the strong cultural mores that underpin being a Gypsy or Traveller have an overriding influence on individual bereavement experiences, so much so that the culture is embedded throughout all aspects of the research as an overarching element of the whole study. The key theme of socio-cultural characteristics explores how the subthemes of personality characteristics, patterns of death and death ritual and belief impact on individual bereavement experiences.

The subtheme of personality characteristics, as the title suggests, looks at the individual personality characteristics that influence grief responses and the personal management of bereavement experiences. This includes resilience, stoicism, gender roles and health. The theme patterns of death discusses the prominent modes of death identified in the study; these include the frequent multigenerational losses families experience, such as high infant mortality, stillbirth and miscarriage, sudden and traumatic deaths such as suicide. The final subtheme is death ritual and belief which considers the strong continuing bonds and relationships with the deceased, the importance of rituals and the burial place and the religion.

Family: This is the second key theme within which the subtheme of relationships explores the impact of relationships on bereavement and grief considering close family, kinship and community relationships. The second subtheme of children will consider the inclusion of Gypsy and Traveller children in death rituals, how early childhood experiences impact on later life experiences and children's understanding and experiences of bereavement and grief.

The theme of support, much like the cultural themes are embedded throughout all elements of the study, therefore the theme of support draws the study together to establish if the close

kinship relationships, cultural norms and community practices offer effective support following bereavement.

Phase 6: producing the report

Braun and Clarke (2006) suggest that the aim of this phase is to tell the story of the data using data extracts to illustrate and validate themes. The report should accurately reflect the social world and accounts of the participants, identifying the complexities and nuances found in the data but remaining grounded in the participant accounts and keeping the participant voice central to the interpretation of the data (Ritchie et al 2014). Using data extracts or segments of the stories is fundamental to this study as the participant voice poignantly illustrates both the personal and cultural elements of the bereavement experiences in a way that researcher interpretation could not effectively replicate.

Throughout the research there were particular stories, or elements of stories that were more significant and meaningful than others, narrative B's story was one of these. As the data analysis unfolded it became evident that B's story encapsulated most of the overarching and sub themes that were emerging from the data. Thus this story became a useful bench mark for analysing and contextualising the research findings. This story was then analysed using information gained from the literature review to explore the bereavement experiences and grief responses situated within the cultural norms and community practices associated with being a Gypsy/Traveller, (see appendix one for B's story and analysis).

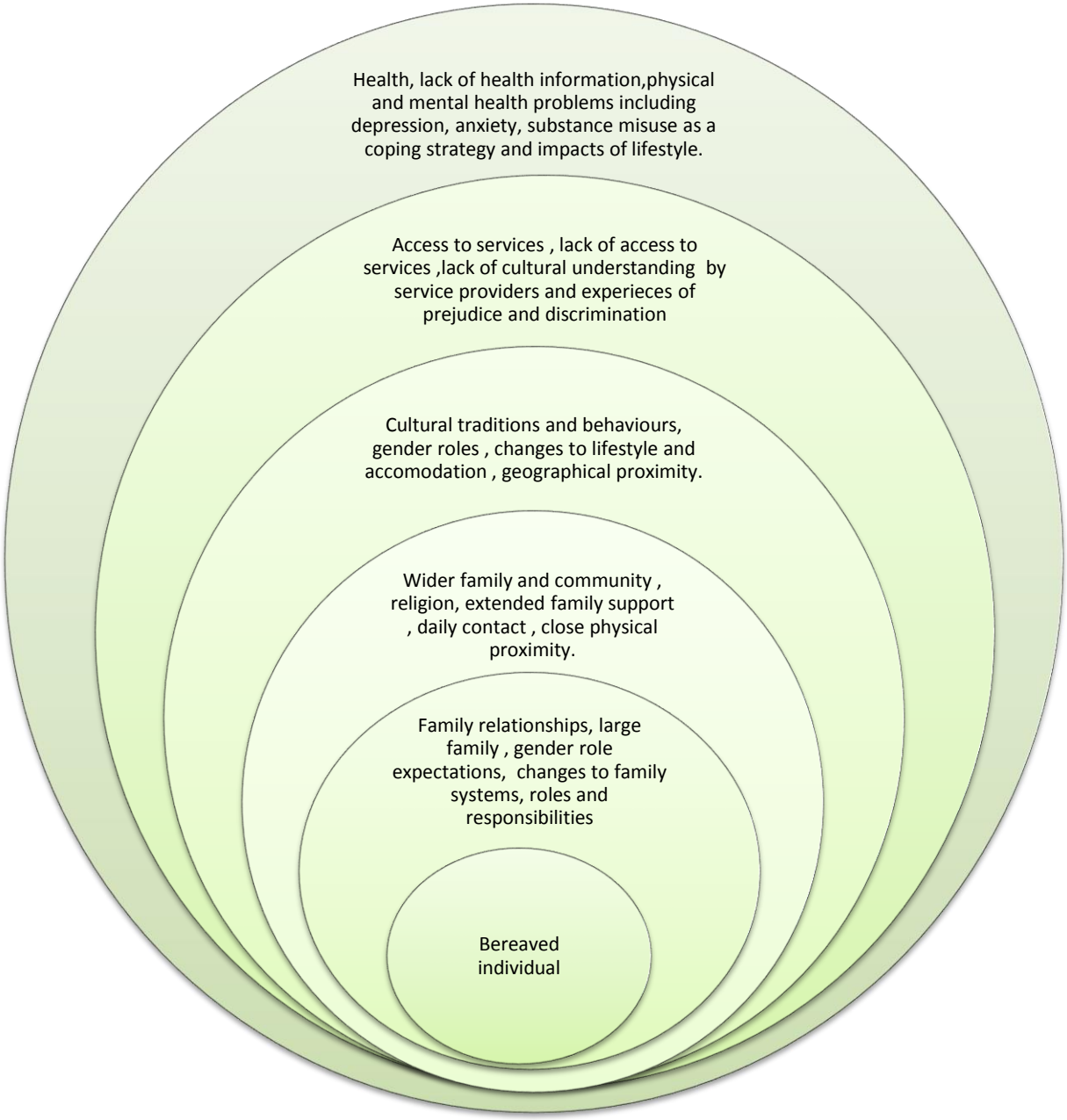
The data analysis and subsequent findings, which are discussed further in the next chapter, confirm the previously anecdotal evidence that multiple intergenerational and often premature bereavement experiences have a negative impact on the health and wellbeing of Gypsies and Travellers.

Sphere of influence

The diagram below shows a visual representation of the factors affecting bereaved Gypsies and Travellers, presented as a sphere of influences, here the key themes found in this study are linked to an ecological framework (Bronfenbrenner,1979) situating the bereavement experiences of Gypsy and Traveller families within their own culture, traditions, and wider social policy.

Bronfenbrenner's (1979) ecological systems theory uses a model that locates human development within a series of interconnected environments that nest within, and impact on each other. This model identifies a series of systems that interrelate with each other determining behaviours, development and experiences. From this perspective human development simultaneously influences, and is influenced by the surrounding environmental systems of family, community and society. Thus the health and dispositions of the individual influence and interact with family functioning and family functions are in turn influenced and shaped by cultural and societal conventions and social policies and behaviours of the social group or society (Bronfenbrenner,1979, 2005). The ecological model is evident in the social structure of western society today, as a cyclic structure of influences of the societal and political influences on the family. At societal or social group level the ecological model provides the social organisation and cultural structure of the society or group. It is noteworthy that Bronfenbrenner recognised the significant impact that cultural differences have on ecological environments. Thus whilst there are very strong family and community networks there can be significant barriers rather than connections when the ecological environments of Gypsies and Travellers as ethnic minorities interact with those of the wider majority population particularly when accessing universal services.

Figure 3. Sphere of Influence



Chapter summary

This chapter has outlined the philosophical framework for the study, situating the inductive thematic analysis used within the phenomenological framework of the study. A detailed consideration of the ethical sensitivities surrounding bereavement research is also discussed. Moreover the chapter has discussed the procedures and methods used within the study; these include participant recruitment, focus group and narrative interviews and the models and processes used to analyse the data. Although analysis in qualitative research threads throughout the research process, rather than being the end process as in quantitative research (Cresswell, 2013), this chapter explores how the themes were developed using Braun and Clarke's (2006) model of thematic analysis.

B's story (see appendix one), provides an example of a narrative interview and analysis applying the key themes identified across the data set. This clearly illustrates the long term impacts of bereavement on Gypsy/ Traveller families, highlighting the barriers that close kinship family relationships and protective behaviours create providing evidence to meet the research aims.

The following chapter explores the research findings in more detail, using extracts from the narratives to maintain the authenticity of the bereavement stories and keep the participant voice the focal point of the study.

Chapter 4: Research findings

Introduction

This chapter discusses the research findings organised under the key themes identified during the data analysis. The thematic maps on the following pages illustrate how the themes were identified and refined to define the key themes of the study. The overarching theme of socio-cultural characteristics which includes the subthemes of personality characteristics, patterns of death and death ritual and belief, and the principle theme of family with subthemes of relationships and children. These themes and the subthemes within them highlight the factors affecting individual bereavement experiences of Gypsies and Travellers.

In this chapter references to extant literature are deliberately limited and will be discussed further in the next chapter to ensure that the participant voice and individual bereavement stories remain paramount here. Similarly to maintain the authenticity and nuances of the narratives editing is minimal and limited to providing clarity for the reader. This is identified as follows: significant pauses are identified using bracketed numbers; for example, '(3)' would indicate a three-second pause whilst (…) indicates the omission and editing of some text and text within square brackets e.g. [information] are additions made by the researcher to provide clarity or context.

It is arguable that many of the findings from this study are similar to those of other individuals, societies and cultures; this is particularly true of the rituals and behaviours associated with Catholicism. However, there are some culturally specific factors influencing the bereavement experiences of Gypsy and Traveller families, most notable are the very close kinship relationships, protective behaviours and high multigenerational mortality rates.

Figure 4: Thematic map 1.

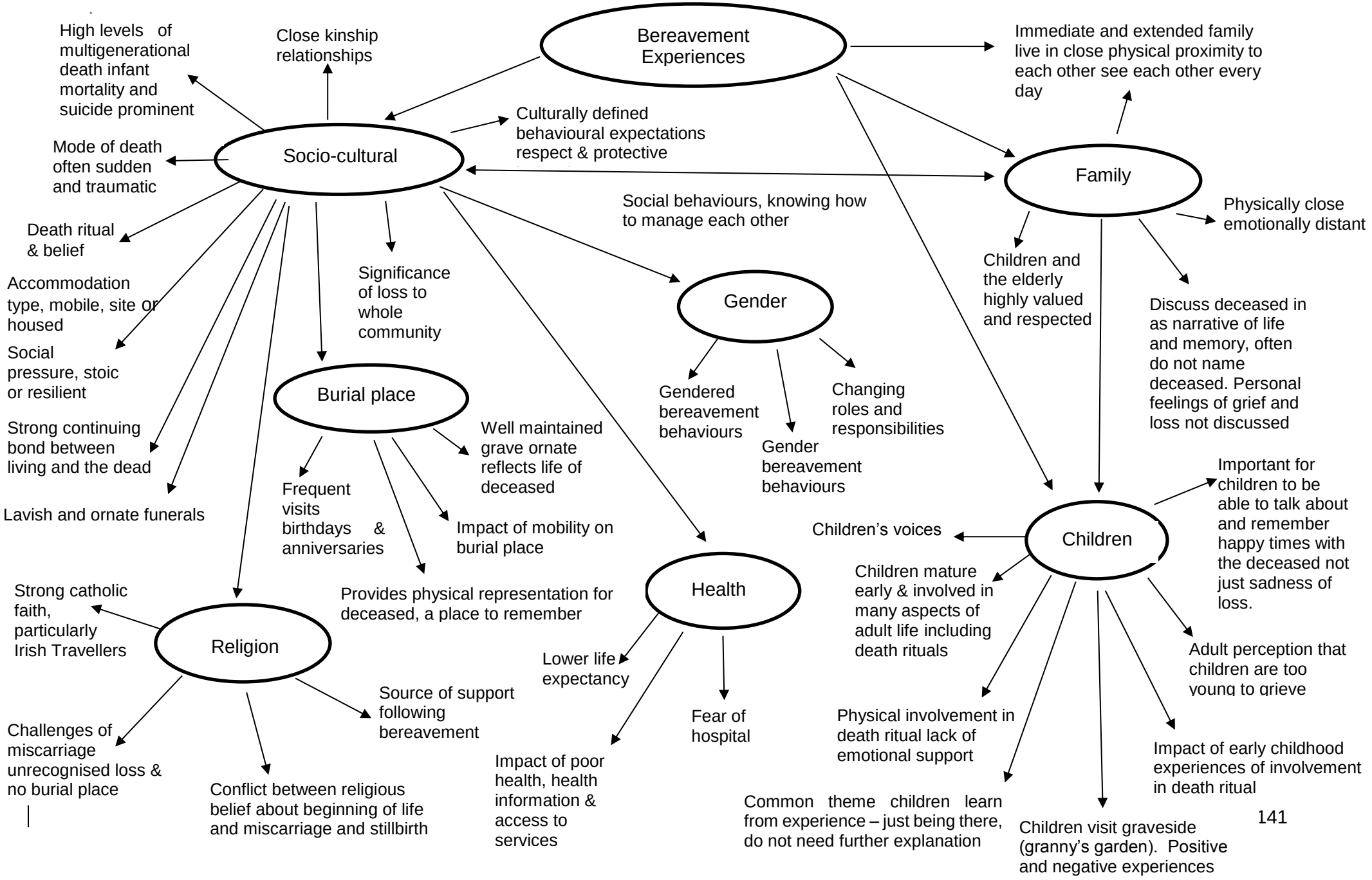


Figure 5: Thematic map 2

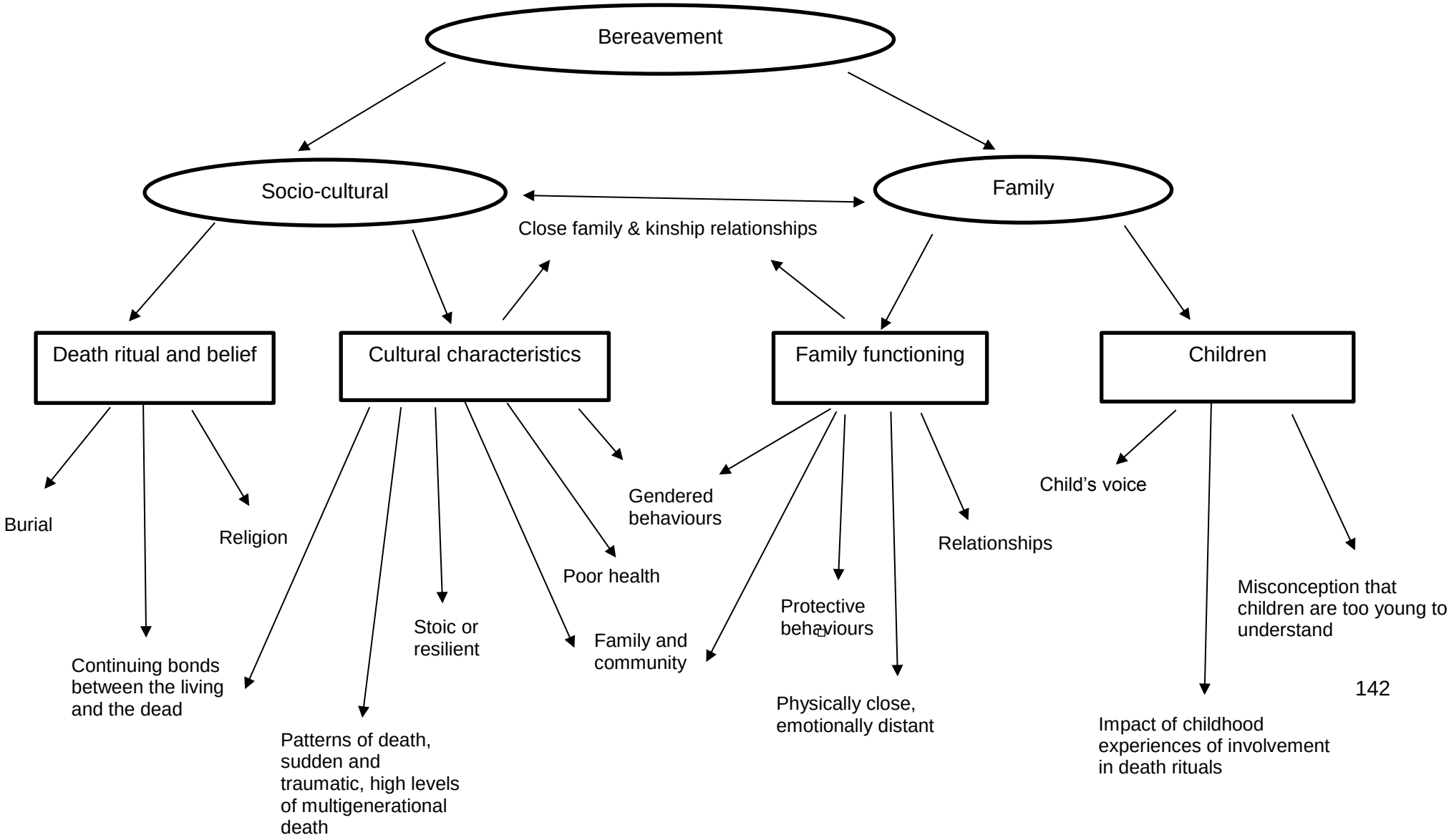


Figure 6: Thematic map 3: Themes applied to bereavement support model

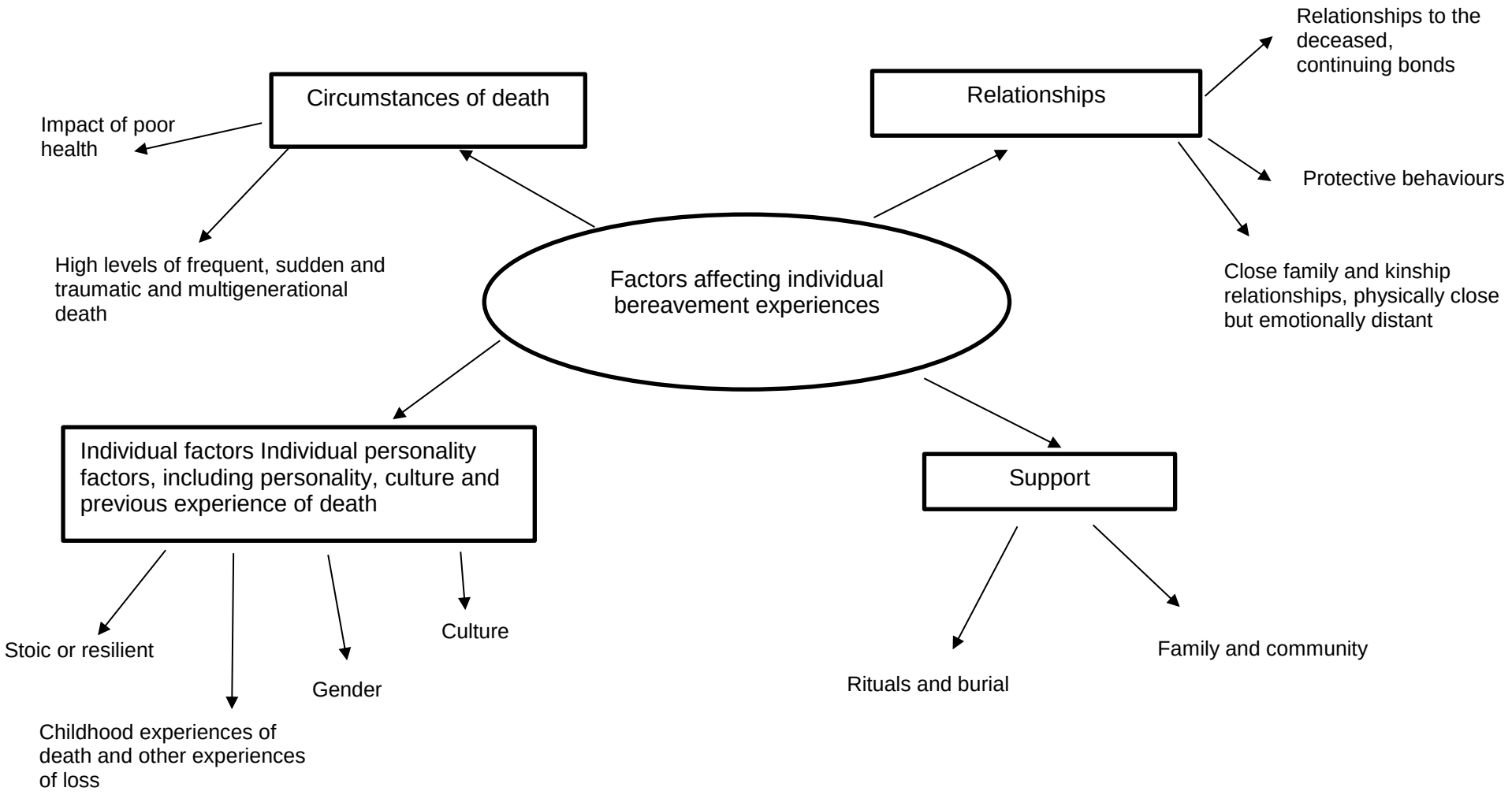
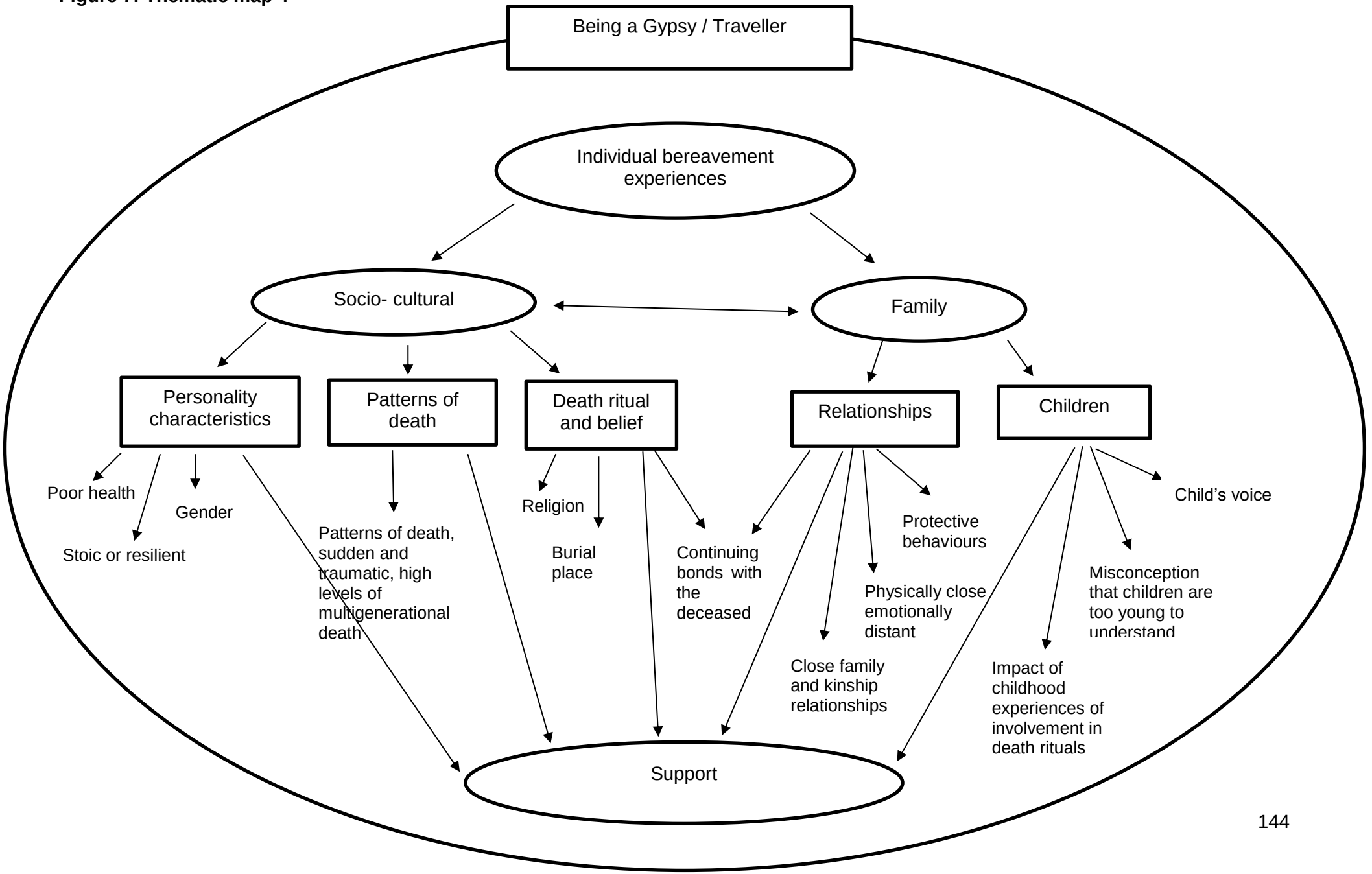


Figure 7: Thematic map 4



Socio – Cultural Characteristics

This overarching theme highlights how strongly socio-cultural factors affect individual bereavement experiences. As the key themes emerged from the data analysis it became evident that not only were socio-cultural characteristics a prominent factor affecting bereavement experiences but that they also underpin the other key themes of family and support as well. This theme considers how socio-cultural factors influence personality characteristics, patterns of death and death ritual and belief. However the wider cultural context of '*being a Gypsy/ Traveller'* encompass

Personality Characteristics

This subtheme explores the personal characteristics that influence bereavement experiences, looking at stoic and resilient attributes, gender and health.

Being '*a good Gypsy/Traveller'* by adhering to the strong moral codes that define behaviours and upholding family reputation underpins the characteristics of Gypsies and Travellers (Clark & Greenfields, 2006). Distinct gender roles and being strong and independent often expressed through stoic attributes, are important features that shape personal characteristics. Stoic attitudes and self-reliance also underpin the health status of Gypsies and Travellers with poor health outcomes normalised within this ethnic group (Smith & Rushton, 2013).

Stoic or resilient?

'*Travellers are very private people, very secretive people and the reason why they are very private and secretive is because there is an awful lot of mistrust out there because to be honest Travellers have been pulled from pillar to post all their whole life there's barriers that*

still need to be broken down for Traveller's and it's not easy for Travellers to express themselves because they like to convince the world that they are independent people' (narrative I).

This narrative summarises the dichotomy of views that characterises Gypsies and Travellers, there are the strong, stoic and independent attributes found within Gypsy/Traveller communities resulting from the challenges they often experience when interacting with mainstream society. The stoic and independent, perhaps even resilient, behaviours developed by interacting with an often hostile and prejudicial mainstream population have become protective behaviours and defining personal characteristics.

The final line in the opening narrative, '*It's not easy for Travellers to express themselves because they like to convince the world that they are independent people'* (narrative I), summarises the fundamental characteristic of being strong and independent, or stoic, that underpins being a good Gypsy/Traveller. These attributes are perhaps the result of resilience developed over generations of living with adversity and prejudice from mainstream society resulting in self-segregation and a '*retreat into the sphere of family'* (Powell, 2013:116). When externally facing the characteristics of strength and independence are protective behaviours against an often hostile majority population, however when inward facing they become a protective strategy towards family members, creating barriers to effective communication and emotional support as each family member seeks to protect each other. Moreover the characteristics of strength and independence are more commonly referred to as stoicism within Gypsy/ Traveller communities, as an aspirational attribute of being a good Gypsy/ Traveller (Smith & Rushton, 2013).

Throughout the study the majority of participants made reference to Gypsies and Travellers being strong, often referring to themselves as stoic, *'Travellers are quite stoical I think' (narrative G).* Stoicism is a strong thread that permeates throughout the study and although

it is seen as a cultural strength it can have a detrimental effect on health and wellbeing by normalising illness and preventable losses (Van Cleemput, 2010). In this study stoicism normalises many of the participants' life experiences including bereavement.

'*I am strong willed person, some people say I have a very hard heart but I don't think that's it I think I am a very strong person. It's the way you feel with grief and what you're made of some are made of chocolate and some of steel. I am a very, very strong made of steel. My family have always said that I wasn't made of sugar and spice I was made of steel. It's about your character; it's what you are made of' (narrative I).*

The narrator of this example was very proud of her strength of character, mentioning it several times throughout her story and attributing the strength or being '*made of steel'* to how she managed her grief;

'*That was it then he had sadly committed suicide, the family were absolutely we were in torment we couldn't believe it. I didn't cry I didn't cry when he died I never shed a tear I never cried, never cried, because it was kinda the way I dealt with the bereavemen*t' (narrative I).

This example perhaps demonstrates resilient characteristics rather than the more commonly expressed stoic attitudes. Whilst stoicism is evident throughout the study only one participant mentions resilience, stating that the Gypsy/ Traveller community has lost resilience with the erosion of cultural heritage.

'*The travelling community had a resilience… I think it has been lost… the culture and language is lost' (*focus group 1).

In this study women referred to themselves and other women as stoic but men are referred to as *'tough men'* rather than as stoic. Whilst there are undoubtedly stoic attributes and behaviours such as the normalisation of the frequency of multigenerational death and loss

the references to being strong and tough may in fact represent resilient characteristics, although not recognised as such within the Gypsy/ Traveller community.

A more detailed discussion of stoic and resilient behaviours linking to extant literature can be found in the next chapter, whilst this chapter continues by exploring how clearly defined gender roles and responsibilities are also significant personal characteristics for Gypsies and Travellers.

Gender

The discussion and findings relating to gender refer to the gendered behavioural differences in the management of grief and bereavement experiences. The majority of respondents across both focus groups and individual narratives referred to the differences in how men and women cope with bereavement as a result of the gender roles, responsibilities and behaviours defined by being a Gypsy/Traveller. The study's findings relating to the behaviours of Gypsy and Traveller men are presented anecdotally through the experiences of women, nonetheless offer an insight into how gender influences bereavement experiences.

Traditionally there are very distinct gender role behaviours and moral codes within Gypsy and Traveller culture which remain prevalent today. Men are expected to provide financial support and protection for the family, depicted through strong masculine roles, often portrayed through aggressive and risk taking behaviours, whereas the role of women is to care for the home and family with primary responsibility for children and the elderly. As well as defining behaviours moral codes also outline acceptable and taboo subjects of conversation; any discussions of a sexual nature are not permissible across genders and generations (Clarke & Greenfields 2006; Matras, 2014).

The strong moral codes surrounding appropriate conversational subjects have been found to impact on bereavement behaviours in this study; the following narrative illustrates the gender

based barriers to communication: *'They can't do that [talk] with each other cause it will be a male ego or a woman's thing (narrative I). T*hese barriers are particularly evident in relation to infant deaths and maternal health as in this extract:

'With my husband when I had the miscarriage you couldn't speak to him about it you couldn't talk about anything that was going on… because they are so private with everything… cause you think that by talking about it your hurting his feelings to so if I am not hurting his feelings I'm o.k. but I'm not it does build up and I got a bit depressed afterwards where it had built up I think' (narrative B).

The challenges of managing grief following miscarriage and cultural boundaries of gendered behaviours that prevent discussion and support between husband and wife are apparent here. The strong culturally defined protective nature and gender behaviours also govern bereavement behaviours, particularly the expression of grief. Both this story and the one below exemplify the differing bereavement behaviours and coping strategies of men and women.

'My sister had a stillborn baby little boy, and my brother in law tried to commit suicide about it. She had photos, and everyone that walked in [she] would show the box, but every time you mentioned the name to my brother in law he took off running he just couldn't cope with the conversation at all so in that case he didn't get what she got, she got to talk about it but he didn't and he tried to take his life about ten times so we were constantly babysitting him. He needed help then but there was nothing like that. Being a man as well he couldn't go and speak to other men about how he felt, he was the head of the family and didn't want to tell the others what he was going through' (focus group 1).

Reflecting on the narrative evidence cultural and gendered behavioural patterns show a more open acceptability for women to grieve and highlights the traditional practice, particularly amongst men of not talking about their loss. There is an acknowledgement of different expectations for men and women, it is acceptable for women to grieve and whilst

recognising that men will feel the loss equally there is a cultural expectation that they do not openly express their grief.

'*The men like to pretend they're strong, and men don't cry and its always, it's the attention is given to the mother Travellers don't realise that the father is feeling every bit as bad he's feeling the same loss, he's got to be strong, he has to have that male ego, the men don't cry he's not allowed to cry and all that but he's just buried his son* '(narrative I).

Conversely the opposite is evident in the findings from the focus group with English Gypsies as this example illustrates.

'*At the graveside that's the only time that our tough men cry, it's the only time you will see them openly cry with no shame or embarrassment. There is no oh he shouldn't be crying, it's their time when they can show their emotions, however they feel'* (Focus group 2).

Whilst these extracts suggest some diversity between Irish Travellers and English Gypsies, the expression of grief for English Gypsy men is constrained to the graveside. So whilst the graveside provides an acceptable place for the expression of grief, once they leave this emotional space there is an expectation that they will then refrain from overt emotional responses and revert to being '*tough men'* not discussing their loss and often resulting in the suppression of grief. The graveside is an important and frequently visited place, providing an acceptable place and emotional space to be close to and grieve their loved ones. The significance of the graveside is exemplified by the relaxation of cultural behavioural norms as an acceptable place for men to express emotion, something they would not normally openly do.

It is clearly evident that across both groups there are stark differences in the bereavement behaviours of Gypsy and Traveller men and women. Although gendered behavioural differences are not unusual when compared to the general population the severity of the behaviours of Gypsy and Traveller men is culturally specific. Most frequent is alcohol or

substance misuse but more extreme coping behaviours include high levels of bereavement suicide, and as in the example below of a Traveller man getting arrested as an avoidance strategy to facing the death of his brother are also commonplace.

'My brother, he could not cope with it and he got himself arrested he just couldn't cope …. To get yourself locked up to go out stealing and get locked up so you don't have to face the reality of what's going on , isn't that enough to say? He deliberately went out and got himself locked up so he didn't have to cope with it. I suppose that's an example of what men will do.' (Narrative I, talking about one brother's reaction to another brother's suicide)

These gender differences in expected behaviours also have an impact on intrapersonal relationship support between husband and wife, a number of participants made reference to the differences between Gypsy and Traveller men and those from the mainstream population, with non-Gypsy/ Traveller men perceived to be more affectionate and supportive.

'Also you have to cope so having to cope with your husband shouting in your ear or shouting into your face whereas if you weren't married to a Traveller you'd probably have someone who'd put their arm around and ask you if you're alright. And moving out of camps and people knocking on the door saying you got to go know you have no time to sit time and worry you have to get out and tow the trailer along the road whilst your children are sleeping' (narrative F).

When there's bereavement in the family if the woman is weak as a woman is, as strong as a woman might be in an emotional sense they are weak and they are the sole keeper of the travelling man. Cooking, cleaning, being there and a travelling man expects his wife to in spite of what goes on, like any man the way men can be strong like that and not think and a lot of the travelling men is not very affectionate you know, or very helpful. A lot of them will even blame the wife when bereavement happens, you know it will come out in an argument; it gets thrown back, if it wasn't for you she wouldn't have died' (narrative C).

This story refers to the gender stereotypes of women being weak and men strong but also alludes to women as emotionally strong and is perhaps referring to the stoicism or resilience that is apparent in Gypsy and Traveller women. Both of these stories suggest that women do not receive empathy or support from their husbands. In fact there is some evidence that the behavioural expectation for men to suppress emotional responses and be tough is demonstrable through aggressive and abusive behaviours towards their wives and children as one third of the participants refer to difficult or abusive relationships. The following narrative provides an example of this, suggesting that bereavement and prolonged grief underpins abusive behaviours for this individual.

'*My husband has been badly affected, he's never got over it and is now very abusive to me and me children, if he'd had help it might be different… so there's me now and my children who are falling in for what happened to him years ago'* (narrative D).

In light of these stories it is evident that Gypsy and Traveller women have particularly challenging lives The difficulties of a travelling lifestyle, maintaining family cohesion and managing marital relationships are further exacerbated by bereavement meaning that they '*do not have time to grieve'.*

'We do expect a lot of ourselves we have to cope with everything, to carry on with family life; you almost haven't got time to grieve. More so with the women the men go straight to drink they start drinking before the body is cold. So then the woman has to manage with her husband, family, kids, it's hard you know. That's what causes more problems for the woman it builds up and builds up you just don't know where to go with it once it's there you don't know have to manage it what to do with it or how to get rid of it. It's part of being a Traveller, it's what they do and unfortunately that brings a lot of problems' (narrative B).

These stories provide an insight into the challenges that Gypsy and Traveller women face. They have particularly stressful lives, not only are they responsible for the family, as carers for children and the elderly, but also, as illustrated in the above narratives, some women

have to manage volatile and abusive martial relationships. In addition the often difficult living conditions, particularly on the roadside, and central role as carers puts women at the forefront of dealing with mainstream health and education services and with social exclusion and prejudice (Acton,1997, Ryder, Cemlyn & Acton, 2014). Given the challenging and significant responsibilities of Gypsy and Traveller women it is easy to see why they overlook their own health and wellbeing and feel that they do not have time to grieve.

In summary the culturally defined gender behaviours that govern the daily life of Gypsies and Travellers also impact on bereavement behaviours, influencing the expression and management of grief. The practice of protecting each other by not discussing grief and loss extends across family relationships including between husband and wife, therefore by not talking to each other they create more tension exacerbating the physical closeness and emotional distance found in their relationships. Moreover the differences in how men and women manage (or do not manage) their grief has significant and long term health implications with women commonly suffering from anxiety and depression and men resorting to alcohol or the more extreme bereavement suicide (Parry,2004; Cemlyn et al, 2009; AITHS, 2010).

Health status

The health status of Gypsies and Travellers is widely recognised as '*significantly poorer'* than the majority population (Parry et al, 2004:1). Much of this is accredited to the difficulties in accessing health services, as illustrated in the literature review and in the narrative from focus group one relating to maternal health care discussed on page 167. As a result of the lack of general health care illness is often severe before medical intervention is sought and often results in hospitalisation (Rushton & Smith, 2013). Hence hospitals are feared and associated with death. Moreover hospitalisation separates the family which is particularly traumatic for Gypsies and Travellers given their close kinship relationships. The difficulties

that this creates are emphasised in the first two lines of the narrative below by the repeated statement '*it is very traumatic'.*

'Sickness to us unless we can handle it ourselves, it is very traumatic, we go to hospital we know it's the best place to be but it's very traumatic, if you have a sore toe and have to have some surgery may be for an ingrown toenail if you're in hospital it's a big massive thing so if a person becomes ill its critical to us and we're there every day just believing this person is waiting for death, so we have to be there for them' (focus group 1).

The stoic and self-reliant nature of Gypsies and Travellers means that they are reluctant to admit to ill health, needing to maintain the strong, tough and independent image they take pride in. This is in part to protect and not upset other family members, but also as a result of the fear of death and separation from family, seen as an inevitable consequence of illness (Parry et al, 2004). The physical closeness of families means that both immediate and extended family members see each other on a daily basis. So for some hospitalisation or death is the first time they will have been apart.

' *To be there all the time even if it kills you, travelling people say we will give our heart and soul just to make them better, and so you think by physically staying there with them it is going to help them. The Gypsy and Traveller community do bedside vigils if they are not a member of that family, every sick and ready to die, they do stay that's why you will find big groups of them at hospital or at home, close the door, the kettle is on the boil, they will never be left on their own and where possible they will be brought home, cos most Gypsies and Travellers want to die in their own bed not someone else's'* (focus group 1).

This example highlights the need to maintain the close physical proximity between family members albeit at home or in hospital. In addition to maintaining close family and kinship relationships, showing respect for the dead or dying is a fundamental cultural behaviour and contributes to the large numbers of Gypsy/Travellers maintaining bedside vigils. The extract

below exemplifies some of the challenges that make being in hospital difficult for Gypsy and Traveller families.

'Hospitals could be a bit more understanding, It's like we had my dad seriously ill and there was a fairground family they had a family member come so there was about 30/40 of our family and 30/40 of their family and we are sitting around and on the floor and the hospital couldn't cope and said why can't you go home and we said you can't tell us that it's the wrong thing to say to us, they couldn't understand that the place we wanted to be was there. You have to be there, the most people did was sit in the car park in the middle of February and froze there' (focus group 2).

This narrative is a good example of the cultural mismatch between the traditional practices of Gypsy/Travellers and the lack of cultural understanding in universal health services. Moreover the trauma that hospitalisation creates mentioned in these stories is attributed to the close familial relationships and fear of death but also to the challenges Gypsies and Travellers face in trying to maintain their cultural beliefs and practices within the mainstream society's domain, the hospital, where universal service provision does not always understand or meet specific cultural needs (Matthews, 2008; Van Cleemput, 2010).

Patterns of death

This theme identifies the distinct modes and frequency of deaths experienced by Gypsies and Travellers, which in many instances are linked to the poor health status of Gypsies and Travellers.

The bereavement experiences shared by the participants of this study are illustrated in table three on the following page, which summarises the losses discussed in each narrative conversation. Some focused on one significant loss whilst others refer to the deaths of a number of family members. Similar stories and patterns of death were also reflected in the focus groups. Interestingly the focus groups did not offer the same level of personal detail as

the narrative conversations as table three illustrates. In the focus group conversations some, but not all of the participants shared personal bereavement stories. These stories discussed similar patterns of death to those in the individual narratives, the deaths of parents, grandparents and children mainly through miscarriage and stillbirth, but differed in that there was less personal detail; the ages and modes of death are not always identified, with more generic discussion in a broader socio-cultural context. Most noteworthy about all of these deaths are the high number of infant, child, early adult deaths and the modes of death, many of which can be attributed to the adversities of Gypsy and Traveller lifestyles, risk taking behaviours, poor health literacy and health care, as discussed earlier in the literature review.

Table 3 Modes of death.

Narrative	Relationship of deceased to participant	Age at death	Mode of death	Explanatory comment
Narrative A	Mother	59	Cancer	
Narrative B	Nephew Children Cousin	Pre -natal Pre -natal 9	Stillbirth 3 Miscarriages Undisclosed	Discusses loss of children here but also participated in focus group 1 as participant B where she discussed the death of her mother.
Narrative C	Son	Late thirties	Substance misuse	
Narrative D	Brother in law Brother in law Cousin	16 21 7	Road traffic accident Road traffic accident Road traffic accident	All three deaths occurred in the same road traffic accident
Narrative E	Uncle Grandfather	30 Undisclosed	Sudden, cause unknown Sudden , cause unknown	Also participated in focus group one as participant E who mainly discusses her uncle here with brief mention of the death of her grandfather who is discussed in depth in the focus group.
Narrative F	Children Mother	2 weeks Pre- natal undisclosed	Meningitis 5 miscarriages and stillbirths Head injury	
Narrative G	Child	Pre- natal	Stillbirth	
Narrative H	Child Grandson Brother Sister in law	15 months 23 33 38	Gastro enteritis Sudden (possible suicide) Cancer Blood poisoning	Death caused by fall from bridge, unclear if accidental or deliberate.
Narrative I	Brother Cousin Cousin Cousin Cousin Aunt Niece	39 28 54 24 41 37 3 weeks	Suicide Suicide Cancer Pneumonia Suicide Cancer Sudden infant death syndrome (SIDS)	5 deaths within19 months
Focus group 1				
Participant A	Grandchild	Pre-natal	Stillbirth	
Participant B	Mother	Undisclosed	Respiratory disease (anticipated death)	
Participant C	Grandmother	Undisclosed	Undisclosed	
Participant D	Children	Pre-natal	2 miscarriages	
Participant E	Grandfather	Undisclosed	Sudden , cause unknown	Refers to early childhood experience and memory of loss of grandfather age 4 yrs old
Participant F	Children	Undisclosed	Sudden infant death syndrome	
Participant G	Mother	Undisclosed	Unknown	Adult recollection of childhood loss of mother aged 5 yrs old
Participant H	Children	Pre-natal	3 miscarriages	
Focus group 2				
Participant A	Mother	Undisclosed	Undisclosed	
Participant B	Mother Father	Undisclosed Undisclosed	Undisclosed Heart attack	
Participant C	Sister in law	30	Road traffic accident	

Although the individual narratives provided more detailed accounts of the losses, with age and cause of death identified more than in the focus groups the modes of death across both narrative conversations and focus groups are similar. In focus group one most of the participants shared examples of their bereavement stories reinforcing the high number of infant deaths found in the narrative conversations. In focus group two the discussion was more focused on one or two deaths which were used as a catalyst for discussion of broader socio-cultural traditions, behaviours and practices relating to bereavement, loss and grief.

Two participants, narratives B and E also took part in focus group one, participant B talked about the loss of her mother in the focus group but in the narrative conversation the loss of children within her family, both her own losses and that of a nephew and cousin. Whereas participant E mentioned the same deaths, those of her uncle and grandfather but discussed her uncles death in detail in the narrative conversation and her grandfather in the focus group.

The striking features of this table are the modes of death and age at which death occurred, many of which are potentially preventable losses when compared to the mainstream population. For example within the mainstream society the death of a fifteen month old from gastro-enteritis is unlikely today. Although a common childhood illness in the UK only seven per thousand cases require hospitalisation. Current mortality rates for this condition are mainly attributed to developing countries and minority populations such as Australian Aboriginals (Elliot, 2007). Similarly the death of a twenty-four year old from pneumonia is unlikely within the mainstream population, further reinforcing the disparity in health between majority and minority populations. Furthermore the table confirms that many of the bereavements experienced are sudden, unexpected and often traumatic with high numbers of road traffic accidents, suicide and infant and childhood deaths.

As discussed in the literature review, the loss of a child is one of the most traumatic bereavement experiences (Stroebe, Schut & Finkenaur, 2013), one which sadly for Gypsies and Travellers remains disproportionate in comparison with the mainstream population.

Infant mortality and maternal health

This study's findings confirm high numbers of infant and childhood deaths in Gypsy and Traveller communities, two thirds (66%) of the individual narrative participants experiencing the death of children in comparison to national statistics of 3.9, (0.4%) deaths per 1000 live births (ONS, 2014).

'I lost five [children], stillbirths, miscarriages and premature birth. But a lot of trouble comes with it and you know when you have nervous systems and what's that word anxiety, depression and all that and all that comes with it' (narrative F).

The example above illustrates the multiple losses often experienced by Gypsy and Traveller women. Unfortunately the stoic nature of Gypsy/ Traveller women and poor maternal health care, often as a result of poor living conditions, results in high infant mortality rates remaining commonplace and normalised within Gypsy and Traveller communities;

'*Tragic, no one questioned the loss, the amount of children, we didn't realise how many more Traveller children died' [than the majority population]* (narrative G).

The loss of children, particularly from miscarriage was a prominent cause of death for the women in this study, fundamentally as a result of poor maternal health care. The narrative below suggests two reasons for this; firstly a lack of consideration for personal health and wellbeing, resulting from family care responsibilities and putting others before themselves, and secondly the difficulties of accessing health services and maternal health care particularly if on the roadside.

*'Even housed Travellers find it difficult to see to them [doctors]. They feel they have no need to see to themselves, they don't care about their health they don't care about themselves. I would say it's a lot easier to access that service if you are housed. You can imagine the difficulty when you are travelling. I don't mean the site, there will be a lot more help there, but when I had my miscarriage I was out on the roadside so I do know that the whole situation of being on the roadside... It's a lot easier to do if you're settled than on the roadside. You had to get on and you had to look after the other children, feeding them every day so you put that aside and get on with the rest of the day and it ended up with me being seriously ill for 3 weeks in hospital because of that. At the roadside it is so wrong and I think it's why so many die in childbirth cos of the moving around, they haven't got their check-ups and everything. Mothers die in child birth because they don't know on the roadside' (*focus group 1).

The loss of a child at any age is particularly difficult but pregnancy losses, miscarriage and stillbirth often remain socially unrecognised (Murphy, 2012). The following example highlights the challenges women face following a loss during pregnancy, particularly poignant is the distinction between a stillbirth which is socially recognised with a funeral and grave to visit and miscarriages which do not have the same recognition of life and death. In this story the cultural and religious beliefs about when life begins, lack of a physical presence to mourn, and lack of social recognition of loss exacerbates maternal grief responses following a miscarriage.

'*We believe that from the first minute you find you are pregnant that is a baby so any Travellers having a miscarriage it is heart-breaking. I do think too that because there is no baby to be seen, they think just get over it and it's not so easy for a mother to get over it. There was an old saying, get on and have another but it doesn't make up for the one you lost. I think as well perhaps as we talked earlier, with the funeral you have the opportunity to say goodbye but with a miscarriage there isn't the opportunity to do that. I've had two*

miscarriages and when it was going on and it felt like the end of the world but in a matter of days, everyone was getting on things and you feel why are you being so soft why am I sitting like this, you have children to look after. So you felt as if you had to, you felt you had to be the same as everyone else' (focus group 1).

This story suggests that peer pressure and family responsibilities impact on maternal grief following a miscarriage. Moreover as cited in narrative G earlier, the frequency of both pre and post- natal loss normalises the loss of children, particularly to miscarriage and stillbirth. Nonetheless these losses have a significant and sometimes long term effect on mental health, as seen here:

'A lot of trouble comes with it, you have nervous systems and what's that word anxiety, depression and all that and all that comes with it' (narrative F).

The bereavement experiences of these women who feel unable to grieve for their children mean that they may experience disenfranchised and complicated grief reactions resulting in depression and anxiety as stated above.

Suicide

Suicide is also a significant cause of death highlighted in this study and alongside high infant mortality is normalised, yet feared within Gypsy and Traveller families and communities, accepting high mortality rates as inevitable rather than preventable. The prevalence of suicide was evident throughout the focus groups and narratives. For example narrative I experienced three suicides within a nineteen month timespan, one of which was a bereavement suicide (suicide following bereavement). In narrative H the cause of death is unclear but possibly suicide and in narrative E the cause of death unknown (see table 3 above). In both of these examples the deceased young men fall within the most vulnerable age group for male suicides, which nationally is between the ages of twenty and forty nine

(ONS,2014) and more specifically for Gypsy/ Traveller males is under the age of thirty (AITHS, 2010). However suicide is not exclusive to young men as this example elucidates:

'*There's a lot of Travellers that commit suicide that have been in completely different circumstances than my brother… a week after he committed suicide my cousins daughter, 28 years of age did it ...My cousin, he said to his wife I am going for a walk and three hours later they found him hanging. To watch my uncle now grieving the man is just besotted but then there is a difference in circumstances he found his son dead can you imagine to walk into a field and see him hanging there. He actually stood there and cut him down*' (narrative I).

This example highlights the prevalence of suicide with three members of the same family committing suicide within a nineteen month timespan.

Bereavement suicides are also commonplace and a consequence of the pressure of culturally protective behaviours meaning that grief responses are internalised rather than shared and supported as the narrative below suggests.

'*The majority of Travellers committing suicide in rural [areas] are on the roadside, most of the ones that I know of are after a death…I think that could be the cause of a lot of suicide as well when nobody is getting to say what they feel, and kept it to themselves and that's why you get a suicide that follows a death'* (focus group1).

The patterns of loss identified here provide an insight into the complexities and frequency of the bereavement experiences of Gypsies and Travellers providing an understanding of why they may experience complicated grief. The following narratives also confirm the associated health implications of mental health problems, referred to as *'nerves'* and the use of alcohol and self-medication as coping strategies.

'Bereavement will go on for ten maybe fifteen years, they don't have the knowledge, they live on their nerves, they start taking pills and drinking, that's the effect it has on them because they are not handling it properly' (focus group 1).

'*A lot of the travelling people when there is bereavement they do need help because they suffer with nerves anyway and a lot of them drinks and that doesn't help, they think because of the psychological problems as well because a lot of them don't go to the doctor a lot of them that takes medication takes it with the drink and that's very dangerous they haven't got understanding or the knowledge about it they think cause they have had a drink once and taken an anti-depressant and nothing happened they think they can do it all the time and it catches up*' (narrative C).

In summary the health status of Gypsy and Travellers is influential in determining some of the modes of death experienced. As a consequence of poor health outcomes mortality rates are high, increasing the frequency of loss and bereavement experiences within Gypsy and Traveller families. Poor health outcomes not only influence patterns of death but also affect the grief responses of the bereaved, increasing vulnerability to complicated grief reactions.

The patterns of death identified in this study, sudden, traumatic and often premature deaths, some of which result in multiple losses over a short time span increase the likelihood of complicated grief reactions. Moreover stoic attitudes normalise poor health outcomes and the patterns of death experienced by the participants of this study, also increases their vulnerability to complicated grief reactions. Indicators of increased vulnerability to complicated grief reactions include sudden and traumatic loss such as suicide, premature deaths including infant mortality and those related to poor health and disenfranchised losses such as miscarriage and stillbirths. In addition multiple losses, either cumulative, a number of losses over a short period of time, or multiple losses from one event are also more likely to result in complicated grief reactions (Thompson, 2012). All the modes of death leading to complicated grief are evident in the bereavement stories shared in this study. For example

in narrative D a road traffic accident resulted in the multiple losses of three family members. Narrative F had multiple miscarriages and stillbirths and narrative I the cumulative losses of three deaths by suicide. Comparative evidence of the frequency of sudden and traumatic deaths within the wider Gypsy / Traveller society is apparent in the recent fire on a Traveller site in Dublin that claimed the lives of ten members of one extended family (BBC, 2015).

Whilst the prevalent modes of death are sudden and unexpected it is important to remember that some, such as cancer, are preceded by terminal illness and so anticipated deaths. Unlike the sudden deaths anticipated deaths give the family time to come to terms with loss and say goodbye, sometimes through anticipatory grief responses. However this does not necessarily ease the process of grief.

'I think that's a big thing when you have someone you know is going to die because it is a long haul all the way through and a different type of grief. It's traumatic with a sudden loss but different when you are waiting. I don't know what's worse if someone has something like cancer when you know you have time to prepare yourself or if someone has a car accident and you don't have a chance to say goodbye' (focus group 2).

Death ritual and beliefs

This theme explores how the death rituals and practices identified within this study provide support for the bereaved. Given the importance of demonstrating respect for the dead it is not surprising that showing respect underpins many of the rituals and bereavement behaviours of Gypsies and Travellers.

The most commonly recognised death ritual associated with Gypsy/Travellers is the burning of the trailer; this was mentioned in some of the stories but as a past tradition that rarely takes place today. The change in tradition is in part due to the value of modern trailers, which instead of being burnt are sold to the non Gypsy/ Traveller population, and to the

increased numbers of Gypsy/Travellers settled in housing (Okely, 1983, Clark & Greenfields, 2006).

'When someone dies we sit up, we have wakes, we believe when someone dies, that's it no sleep just constantly sitting up for that person. We bring them back to their home. Traditionally the Irish Traveller would stay for 3 days and would then burn the trailer and then the funeral and on and off for about 3 months, times have changed' (focus group 1).

'*The Romani's sitting up all night before the funeral, say the funeral was tomorrow they'd sit up all night, and some of them did burn their caravans as a matter of fact I lost my little boy at fifteen months suddenly and my brother in law who's traditional said to burn the caravan I said no he was born in that trailer I would rather give it away in the end we sold it for a little bit of money'* (narrative H).

These stories show the similar practices of both Irish Travellers and English (Romani) Gypsies, both of whom discuss the changes in the ritual practice of burning the trailer and the other main death ritual of 'sitting up' which continues to be a fundamental practice following a death. The origins of these rituals, as discussed in the literature review, are unclear but particularly for Irish Travellers there are links to their strong Catholic beliefs as 'sitting up' is essentially a wake.

Demonstrations of respect are most evident in the often extravagant funerals that are common to Gypsy and Traveller communities. The lavish funerals and ornate headstones, which often include imagery such as horses and wagons, reflecting the life of the deceased, are an important demonstration of the highly respected and valued place the deceased held within both family and community (Parker & McVeigh, 2013). Moreover the showing of respect and extravagant funerals also demonstrates the importance of the place that the dead maintain in the lives of the living. This is apparent throughout the study as these extracts demonstrate;

'*Someone dying they are given more respect than at any other time, they say showing respect is about how big the flowers are'* (focus group 2).

'There must of been hundreds and hundreds even thousands a big lorry load, a lorry loaded up, the hearse loaded up other cars, vans, small trucks all loaded up with wreaths. Its tradition peopled like to show they know they're thinking of them' (narrative H).

These excerpts refer to the use of floral tributes used to show respect for the dead, the floral arrangements are often representative of significant aspects of the deceased's life, as in this example;

'He used to have a yellow metro so my uncle brought yellow daffodils made into the shape of a car' (focus group 2).

Death remains at the forefront of Gypsy and Traveller experiences not only because of the high mortality rates but also because of the strong continuing bonds and central place that the dead retain amongst the living. The narrative below further exemplifies the importance of the grave as a physical representation of the deceased and how relationships between the living and the dead are maintained across all generations of the family, with children actively involved in the remembrance and maintenance of continuing bonds with the deceased.

'*My youngest daughter is 14 whatever she does, she wants to go up there [to the grave], if she gets a prize at school, she talks when she's up there she'll say nan I got this this, I've done that. I guess it's a place where you can remember the people, so the children pick up, it is a place where they are, a lot of children are brought up to believe that, but mine are brought up to believe they are in heaven but it's the last place that you can contact them I suppose' (*focus group 2).

In this example visiting her grandmother's grave is a positive experience maintaining a strong continuing bond with the deceased; however for other, younger children this is not the case as the story discussed on page182 where frequent attendance at funerals became an

upsetting experience for one child. Nonetheless the graveside is an important place for Gypsies and Travellers both physically and emotionally.

Given the strong attachment bonds that are maintained between the living and dead the burial place or graveside becomes a symbolic place and physical representation for the deceased.

'I think part of it is getting through your grief but part of it is an extension of your love for that person that is still there, although you are going and you know they're not, it's a piece of ground but at the same time its symbolic'(focus group 2)

It is important for Gypsies and Travellers to be together in death as in life, close family and kin relationships in life continue in death as family members are often buried close to each other in family burial plots.

'*The most important thing for families is where you bury them, you like to think of where they are going, are they going to be with someone they know, it's a big thing'* (focus group 2).

Traditionally Irish Travellers often return 'home' to Ireland and to family burial plots, however as families become more settled this practice is changing and families are buried more locally. It is not uncommon for deceased family members to be moved and reburied closer to family (Brack & Monaghan, 2007). This narrative illustrates the dilemmas families face as changing and less mobile lifestyles influence burial places.

'*Mum took her brother to Ireland but if I had the sense that I had now, if I had the understanding I had now I would have said mum keep him in this country so we can so that we could visit him...At that time he was not married his mum and dad had died so he was buried in Ireland. Since then my dad has died and my brother has died and they are buried here and he is isolated over there, if my mum dies tomorrow and if I die tomorrow we will be buried here. We have lived all of our lives here and we were very close to him as he was always with mum, it was the wrong decision to bury him over there'* (narrative I).

The graveside plays a significant part in the continuing bonds between the living and the dead for a number of reasons, providing a physical representation of the deceased, as a place to be close to loved ones. This is also important in helping young children to understand death and loss as it provides a concrete place for the deceased (Mallon, 2011). Moreover the graveside offers both a physical and emotional space for Gypsy and Traveller men as an acceptable place to express their grief.

The importance of having a physical place for the deceased is further emphasised by the women who have experienced miscarriages and stillbirths. A stillbirth provides social recognition of the loss; the baby is recognised and buried providing a grave and physical place to mourn. A miscarriage does not afford the same recognition of life and death, there is no burial place, or physical marker for loss, there is '*nowhere to go'* (narrative B).

The lack of social recognition and physical place to mourn complicates grief reactions for the women bereaved through miscarriage in this study; their situation is further exacerbated by the fact that some experience multiple miscarriages. Narrative B's story highlights the difficulties as she expresses jealousy of her sister who has a grave for her stillborn child whilst B has nothing for her losses through miscarriage.

'*We buried a baby when she had a stillbirth. When you have a miscarriage you have nothing …you don't have a grave to go to or so we kind of substituted my nephew's grave for all these miscarriages it looks silly in your head but... So in a way you're kind of jealous that she got as far as having something for the rest of her life to go and look at, at least you have a name on a headstone, you have photograph I've got nothing'* (narrative B).

The significance of bereavement and loss through miscarriage is recognised in the extract below where in some instances the Catholic Church are beginning to make provision for women bereaved through miscarriage.

'*The Catholic Church is recognising the mothers and the bereavement they are going and they are listening to the mothers now and the baby should be buried and there is a funeral service for the unborn baby and with the Travellers now it is becoming more frequent. 'Our church what they do, because they help the Travellers, any Traveller woman that lost a baby, because the priest recognised it was affecting the mother badly, anyone with any loss of baby at all, in the back of the church in the garden he gave the opportunity of planting a rose bush and it was a memory bush and anytime you wanted to go to remember the baby even though you never saw its face you went to your rose bush and you can do what you want because you hadn't got a graveside to go to and that felt better that you had somewhere to go and I can go any time'* (focus group 1).

Religion

The initial findings of this study suggested that religion featured prominently throughout the focus groups and individual narratives, however following more detailed analysis it emerged as a subtheme rather than an overarching or key theme. The analysis found that the theme of religion was most prominent for the Irish Traveller participants as they stated that '*the majority of families are Catholics'* (focus group1) and *'we are very religious'* (narrative A). Strong Roman Catholic beliefs are evident throughout their bereavement stories and appear to be the main source of support following bereavement for many of the participants.

Interestingly religious belief did not feature so strongly in the narratives of the English Gypsy participants who talked much more about traditional Gypsy practices and behaviours than religious beliefs and support. However as many of the ritual practices are similar it is difficult to establish the origins as either traditional Gypsy ritual practices or based in religion.

Continuing bonds and relationships to the deceased

This subtheme considers the relationships between the living and the deceased. The strong continuing bonds found throughout the study are epitomised in following statement:

> '*They are in your arms, they live on'* (focus group 2)

This powerful and emotive statement epitomises the place of the dead, amongst the living, although no longer physically present the dead clearly maintain a central place within the lives of the surviving family members. Similarly the narrative below summarises the cultural beliefs and strong continuing bonds that are sustained with the deceased.

'As Travellers you are taught that… they live on. My granddad died before I could remember him but you are taught that your granddad is still there, he is still looking after you and looking down on you, to us they are not gone' (focus group 2).

These narratives suggest that the dead remain interwoven in the lives of the living. The place of the dead is underpinned by the high levels of respect for and remembrance of the deceased by continuing to mark significant dates;

'If it's a birthday, mother's day, father's day, they are very important so you will take something just like you would for someone who is alive' (focus group 2).

The complexities of Gypsy and Traveller family structures that are governed by strong moral codes and distinct gender roles and responsibilities impact on inter-personal relationships of the family. The closeness of family relationships, referred to throughout the study relates to close physical relationships rather than emotional closeness. In fact the protective behaviours, stoic and self-reliant characteristics appear to create an emotional distance.

Family relationships

This theme highlights the complexities of family relationships in which the physical closeness but emotional distance that is created by the overriding need to protect other family members above the needs of the self, results in internalised personal feelings and complicated familial relationships.

'It separates families' bereavement' (narrative C).

This short but poignant statement is perhaps the opposite of what might be expected given the close kinship relationships within which Gypsies and Travellers live. However in these extremely close family and kinship networks the cultural behaviours and practices of *'protecting family at all cost'* appear to be detrimental to and impair personal grief responses, creating barriers rather than support between family members, as the narrative extracts below exemplify:

'We do expect a lot of ourselves we have to cope with everything, to carry on with family life; you almost haven't got time to grieve… If it's a member of your own family, your brother or sister, you can't show your feelings you can't because you are afraid to hurt them, you have to keep a brave face on it' (narrative B).

'*You can't show your feelings…its part of a Traveller, it's what they do, and unfortunately that brings a lot of problems. I think that could be the cause of a lot of suicide as well when nobody is getting to say what they feel, and kept it to themselves and that's why you get a suicide that follows a death'* (focus group 1).

'You've got this overwhelming feeling that you don't know what to do with, it's there for years biting at you' (focus group1).

Reflecting on these responses it is evident that personal grief responses are constrained by socio- cultural behavioural expectations, and whilst it is not uncommon for cultural mourning

behaviours to influence the manifestations of grief (Valentine, 2009; Walter, 2010), the highly protective nature of Gypsy and Traveller families means that personal expression and management of grief becomes internalised in favour of protecting other family members.

The management of personal grief is embedded in the complexity of family relationships and the strong protective attitudes towards other family members found within Gypsy and Traveller communities. The need to protect other family members is paramount above personal wellbeing.

Families will usually live in close proximity to each other and will see each other every day, thus a death may be the first time in their lives that they have been separated (Richardson et al 2007). Although there are close physical relationships the need to protect family members seems to create an emotional distance.

'*My mother, when she lost my grandmother, she was fine cos it took three weeks to bury her because we had to send her to Wales where my grandfather was buried and it took three weeks, but my mother was fine in those weeks, but on the day of the funeral she went hysterical and got severe depression afterwards. Because she didn't let things happen from day one she held it in for three weeks and then just couldn't cope whatsoever. She had a big family, they were all adults, she could have relied on them, she had brothers and sisters but instead she took everything on herself thought she had to do everything but on the day of the funeral she just cracked up altogether and ended up with depression for over a year. I think when you have a large family you should let them share what you have to do rather than take all the responsibility yourself, but because she was my grandmother's carer she felt it was her place to do everything. I think being the grandchild when my grandmother died, all you want to do is look after your mother or father whichever is involved, but being the head of the family, they don't want your help, they are trying to protect you so it's like a vicious circle, you are looking out for them and they for you all at the same time' (*focus group 1).

This narrative illustrates the emotional distance created by a cultural hierarchy in which family elders are highly respected family decision makers with distinct roles and responsibilities that govern social actions and behavioural practices. For women this includes the role of family matriarch and head of the family for domestic issues (Cemlyn et al, 2009). As the narrative above illustrates these complex roles and responsibilities, in this case as a carer at the time of death, create barriers to familial support with the distinct roles and responsibilities and protective behaviours preventing help and support from other family members, thus grief becomes a huge personal burden. Similarly the narrative below shows how the silence maintained through protective behaviours impacted differently on each family member.

'*Years later I started to realise the impact on my family, my mother, grandmother and aunt. The subject had been avoided for years. After my gran died my aunt, she's autistic, told me how upset my gran had been, she grieved to loss of her grandchild but never said anything to protect me. My sister married but didn't have children for ten years, she was afraid that it would upset me if she had a child and also afraid that she would lose her child, she was young , only twelve when I lost my baby and we never spoke about it so she didn't understand. Travellers are quite stoical I think. It was a revelation to me that other people grieved my loss*' (narrative G).

This story highlights the long term impacts of bereavement within Gypsy and Traveller families attributed to the protective practices of privatising grief. Furthermore the lack of opportunity to discuss the loss of the baby resulted in a grandmother unable to openly grieve the loss of her grandchild, a child who grew into an adult fearful of having children of her own and sadly the mother's realisation that other family members also grieved for her loss.

In the following story the severity of the sudden unexpected death of an uncle is demonstrated to children by their father crying, something they had not experienced previously as Gypsy /Traveller men are renowned for being strong and tough and not openly

expressing emotion. Also evident is how early in childhood protective behaviours are embedded as the two older children try to protect their younger siblings. Also reinforced in this story is the need for the family to remain strong despite their grief.

'*We knew something was wrong we heard our father roaring and crying obviously then we had never heard our daddy cry, We were a bit older, our younger brother and sister were really, really small and they didn't understand we were like don't get out of the car cause we didn't want them to hear anything and we were crying so we got out of the car we just didn't want them to hear it. Obviously it had a major impact cause our fathers family experienced their mother died young and their brother died at a young age so it brought memories up again. So the whole family then, it was hard but the whole family still had to be strong but they were grieving'* (narrative E).

Gypsy and Traveller family structures maintain distinct generational and gender orientated roles and responsibilities and moral codes which define familial relationships (Cemlyn et al, 2009). Confirming the existing literature review, the subtheme of gender outlines the strict moral codes that denote conversational taboos within relationships. These restrict opportunities to discuss personal feelings and provide support. For example in the extract from focus group one on the previous page, the family matriarch and carer shoulders the burden of grief to protect her own children, whilst for the children respect for hierarchical family roles prevents them from supporting their mother. The final line refers to a 'vicious circle', whereby parents and children are all trying to protect each other but isolate rather than support each other.

'She didn't want to let her guard down and say what she really felt, it's about wanting to protect other loved ones' (focus group 1).

This example typifies the protective behaviours found throughout the study.

Children

The subtheme of children became an unexpectedly significant theme in both the focus groups and six of the narratives making references to the impacts of childhood bereavement experiences on both participants own early childhood experiences and those of their children.

*'you can't protect the child from the scenes …the children is involved in the process of the death of the person, they go to see them with us, we go to the funeral parlour, to the masses, light the candles, have them at the funeral so initially they wear the hat of what is going on but we don't explain anything to them. They see it all the time and I suppose it is going to affect the child emotionally but I've heard the old people saying, what makes you strong won't kill you, but it needs to be looked at it's a big issue' (*focus group1).

This conversation was a pivotal point in the study, recognising that perhaps children need more emotional support than they receive following a family bereavement. The outcome of this conversation resulted in an additional focus group being organised with children and young people, enabling their views to be included in the study and culminating in the production of a book titled, It's Different without You, (Rogers, 2014) specifically focused on supporting children's emotional needs and responses to loss and death (see appendix seven).

Throughout the study the highly valued and protected place of children within Gypsy and Traveller families was evident, central to family life children benefit from being part of strong extended kinship families and of community structures. This central place of children means that they are included and participate in many aspects of adult life including death rituals and funerals (Okely, 1983, 2008; Matras, 2014). Liegeois (2005) asserts that the place of children within Gypsy and Traveller communities provides them with both physical and psychological security. However whilst physical care needs are undoubtedly well met with

many of the research participants reinforcing how well cared for children are following bereavement particularly by extended family and the community there is, as highlighted in the opening narrative, a lack of emotional support for children experiencing bereavement and the associated death rituals. This reinforces the physical closeness but emotional distance found within Gypsy and Traveller families which is exacerbated by the cultural practice and protective strategy of not discussing the deceased or personal feelings of grief and loss.

Although children are fully involved in the death rituals following a bereavement adult perceptions of the children's experiences were embedded in their stoic approach to life as the final statement in the opening narrative suggests, 'what makes you strong won't kill you'. This stoic or 'tough love' approach and the common cultural belief that children are not affected by loss and the death rituals they are involved in as they are 'too young to understand' means that the protective practices of not discussing the deceased or feelings of grief are also extended to children. The adult beliefs and behaviours that govern children's experiences are summarised here:

'I really don't think bereavement affects children as much [as adults], they are too young to understand' (narrative I).

'*By them being there and being involved they were getting their questions answered'* (focus group 2).

As a result of the misconceptions that children are too young to understand and do not grieve, children experience bereavement and involvement in death rituals without the opportunity to talk about their feelings and experiences, as this example confirms:

'It's a no go area and the child is not spoken to about the person that has died and it's only when they get older, they start to say words, about how they were feeling, or how I felt when

granny died. Talking from experience here, one child was very close to my mother and she never really spoke about anything for four or five years after' (focus group 1).

Hence children do not always receive sufficient emotional support to help them understand and manage their emotional responses and grief, or to develop the resilience necessary to manage their losses effectively. Moreover consideration needs to be given to whether the internalised grief found within adults actually begins in childhood, as it is well attested that early childhood experiences are influential in determining later life outcomes (Allen, 2011; Field, 2010; Marmot, 2010). This is exemplified in the following narratives which illustrate the impact that memories of involvement in death rituals in early childhood have had on later life experiences.

In this story an eighteen year old recounts her experience of the death of her grandfather when she was four years old and how the experience has had a lasting effect on her.

'*When my grandfather died we sat up for two weeks non-stop, never slept, never did anything. It was the hardest thing to do. When I look back it was terrible, knowing that your grandfather was dead inside that room. Even now when I go up to the trailer it is hardest thing cos all you can think is that I can smell it. Ever since I was a little girl dead people smell. It comes back to you, the coldness when you kiss them goodbye they are so cold and you don't forget that cold feeling, and that one bit of taste in your mouth. After my grandfather died I haven't been to another funeral and I wouldn't go. My own cousin has just died I said I can't go I'll babysit the children. I wouldn't dare sit up now not being disrespectful, it's hard, and it's too much pain. When you've experienced the pain you have that fear that you are going to receive that exact pain again'* (focus group 1).

Similarly the following example exemplifies the long term memories and fear created from childhood experiences of involvement in funeral rites.

*'A lot of people in the Travelling community they like to see their dead before they bury them … it was like I had a duty to go in and say goodbye I was only nine or ten when a cousin of mine died that I used to babysit for and I had to go in and see her…(3) It's a hard thing to live with afterwards, you have nightmares about it. It's that last image, it's the one that you never forget no matter how well you knew them when they were alive when you say goodbye when they are dead that's the one that sticks with you not the one where they were happy laughing playing, it might come back to you but the one that sticks is the one in the coffin. Personally I wouldn't advise adult or child to do it if you don't have to I really wouldn't but with the Travelling community it's something they do, it's the last sign of respect, your last way of respect. You said goodbye to show respect but when you're a kid you don't always show respect when fear has overtook your body. so I think if there was someone who could actually sit with a child and explain why they were going to kiss a dead person goodbye you know it might ease it but it didn't for me it was something that was long lasting in my memory I might have been alright if someone had explained to me or give me a good reason why I should be doing it cause I didn't feel like I should be doing it. You haven't nothing to fear so they say; I had a lot of fear' (*narrative B).

This narrative is a good illustration of how cultural practices define behaviours and adult reassurances of *'nothing to fear'* are insufficient without additional explanations and understanding of what is happening. Fear generated by lack of emotional support and understanding is reiterated again in the following story where a child's recollection of the impact of attending multiple funerals demonstrates the effect that early childhood experiences have on how they manage (or do not manage) subsequent bereavement experiences

'The child came back and said please don't take me back to them people's gardens any more cos I don't like them. We used to call granny's grave her garden. She said I don't want to go back to the graveyard to see the gardens no more. I don't like seeing the boxes in

the garden. It messed the child up she was only a baby, even now if she sees a hearse and, she is fourteen now' (focus group 2).

Reflecting on these stories it is clear that there is juxtaposition between the cultural beliefs and behaviours of adults asserting that children are too young to understand and so unaffected by their involvement in death rituals and the lived bereavement experiences that tell a very different story. Highlighting the long term impact that early childhood involvement in death rituals has had on later life bereavement experiences.

These findings are comparable with those of Fitz (2010) whose report on the bereavement care needs of children in Wales found that for Gypsy and Traveller children family support following a bereavement did not extend to discussing death. The findings of both this study and that of Fitz (2010) highlight the gap in emotional support for children following a bereavement resulting from the cultural practice of not discussing death.

Support

The overarching theme of support incorporates both the data gained from the focus groups and narratives and also the questionnaire responses from the initial scoping exercise with external agencies. Although the participant information sheet suggests areas for discussion the focus on support needs differed between the focus groups and the narrative interviews. The more formal and structured approach of the focus groups included focused discussion on both community and external support, whilst the more informal and individual stories shared in the narrative interviews resulted in some of the interviews including discussion on support whilst others did not if it did not naturally arise as part of the story. Reflecting on this theme it is necessary to contextualise the term 'support'. As discussed in the methods chapter the context of support from the researcher's' perspective is as a 'requirement for help' following bereavement. This encompasses both physical and emotional support from a range of sources including family, community, external support services, religious beliefs and

rituals. In contrast within the bereavement stories support generally refers to physical help from family and community, whilst references to specific bereavement support were primarily in response to researcher questions.

As with many aspects of Gypsy/Traveller lifestyles the availability of and access to support is exacerbated by their living conditions. The narrative below highlights the challenges for Gypsy /Travellers in housing or on the roadside who are often more isolated from family and community networks than those living on a site.

'*Someone on a site will have a lot more support than someone in a house and someone on the roadside is going to have nothing at all'* (focus group 2).

Changes in the availability of family support networks are also reinforced in the following narrative:

'I think in the olden days the family was always around you and even though friends and relatives come and be there but you know when they went you would always have the family around but because of the changes in the way of travelling life that support is not there anymore' (focus group 1).

The narrative examples presented here show how family and community support mechanisms are influenced by Traveller living environments as many extended families no longer live in close physical proximity as in the past.

The narrative below outlines the family and community support following bereavement.

'*That's the main thing in the travelling community, doesn't matter if you're cousins, friends, don't matter, in the travelling community everyone supports everyone. 'You just all help each other, everyone mucks in together. There's a lot of tea and sandwiches and the young girls will be sitting in the kitchen making tea and sandwiches and running for milk cos they do that from the minute someone dies until the funeral. It's not just one night and that's it,…the*

whole community gets involved before a funeral. You may have met someone 10 years ago and then someone dies and you'll see them again and the first thing they'll think of is where is the kettle what do you want me to do and everyone is part of a funeral. They never close the door; from the minute someone dies the door is always open until the funeral is over for whoever wants to come in' (focus group 1).

The focus of bereavement support outlined above and throughout the study relates to physical support such as making tea and caring for children for a limited time until the funeral rather than emotional support. Moreover references to individual coping strategies throughout the study suggest that loss and grief are not discussed within the family and wider community for the following reasons, firstly, as a protective strategy towards other family members: secondly the very private nature of Gypsy/ Traveller families hinders community support, which stems from a lack of trust and fear of information shared being used against them at a later date as stated below:

*Travellers are under suspicion that they may go and talk about them; I know my mother…would not want to wash her laundry in public' (*narrative B).

Concerns about the confidentiality of information relating to the provision of bereavement support were reiterated further in the following discussion on service provision.

Service provision

'I think because bereavement is so personal Travellers would feel it's too personal for a non-Traveller to understand or… [how] a non -Traveller bereavement counsellor would help me because at certain stages of bereavement you are not looking for care for yourself and that's a big issue with Travellers they feel that they are not worthy of that' (focus group1).

The final line of the narrative above makes a significant point in determining the bereavement support needs of Gypsies and Travellers, which yet again places personal wellbeing below that of caring for others.

Whilst the majority of the study's participants agreed that there was a need for bereavement support services there was a clear division in the type of support needed, some participants favoured community support as highlighted below:

'It would be good if it was someone from the community that was trained in these skills that would have a guideline that understands the culture, to give proper services for them and specific issues surrounding Travellers would come into the national side of that counselling (focus group 1).

'I think outside help isn't going to help, they don't know anything about the person who died, so they can't say anything to comfort the child, they don't know the situation and how they died. Unless you know the family very well and the person that died you can't really give any support' (focus group 2).

Whilst others favoured external support:

'I also think it would be good to have someone who understood that wasn't from your own family or community, for the reason when it is you, especially if you have kids. Like my mam she didn't want to break down in front of her kids she didn't want to have that conversation with her own children where she would have trusted us more than she would her sisters or other relatives, so just having someone for her to talk to have a release because she would never have done it with us, so I think having someone from outside the community, like a shoulder to cry on she did a lot of crying but at the end of the day she didn't say anything, I think you have to talk about these things sooner or later. It might have saved her a lot of problems if she had someone to talk to them, it's not fair to the one keeping a brave face, having an outsider that they could let release would be better' (focus group 1).

'*I think a lot of Travellers I think they could benefit from bereavement counselling even if they don't go as you say people may not want to open up and but I think it would be a lot if they knew it's there if you know what I mean if they know it's available' (narrative A).*

'If it's a member of your own family, your brother or sister, you can't show your feelings you can't because you are afraid to hurt them, you have to keep a brave face on it... so we probably do need help. From a personal aspect I would rather it was a non-Traveller cause I could open up to them and not worry about if they knew my family. I think the professional whether a Traveller or non-Traveller needs to be trained in our culture. You have to have trust and confidence in whoever it's going to be' (narrative B).

'I think it's good to have the option to talk to someone else to so that you can just vent everything to say whatever you want to say, be able to speak, to just get it out' (narrative E)

'I think I there really is a need for bereavement support but they must understand Traveller culture otherwise its useless '(narrative G).

Although all of the participants recognised the need for bereavement support the narratives above clearly demonstrate why external bereavement support services are not generally accessed. These findings are reinforced further by the results of the pilot scoping exercise carried out with external bereavement support organisations, discussed below.

Summary of findings from questionnaires with external agencies

The results of the questionnaires identified that there is some very limited bereavement support being provided for Gypsies and Travellers in some areas. This is incidental rather than planned and targeted and usually as the result of other interventions and support. For example where medical help is sought it is for associated health conditions such as anxiety and depression rather than any underlying cause related to bereavement and grief.

A common and significant factor found in all the organisations that have provided bereavement support for this group is that it is established as a result of a gatekeeper, or known and trusted person who had an established working relationship with Gypsy and Traveller communities. Specialist organisations such as the Traveller Movement, Friends, Families and Travellers and some Traveller education services have provided informal

bereavement support as a result of other interventions with Gypsy and Traveller families. Cruse, a national bereavement support agency has provided specific bereavement support, but this is again through specialist volunteers who are from Gypsy or Traveller backgrounds, so known and trusted by Gypsy and Traveller communities. The emphasis on a known and trusted person who understands and respects Gypsy and Traveller culture and beliefs is paramount and reiterated throughout responses.

The questionnaires established the lack of bereavement support being provided by specific bereavement support organisations but did identify the role being played by other professionals and such as traveller education and Gypsy and Traveller support organisations who are working with Gypsies and Travellers on other aspects of life such as health or education. These people become trusted by Gypsies and Travellers and identify bereavement as underling issues for their interventions (See appendix four for individual organisational responses).

The narrative statement below effectively captures the fundamental criteria for the success of any bereavement support service, the need to understand and respect Gypsy and Traveller culture, in order to gain trust and provide effective bereavement support.

'How can you come in and tell us what to do if you don't understand us' (narrative B).

This chapter uses the participant voice to highlight the key findings of the research and exemplify the bereavement experiences of Gypsies and Travellers. The findings identify the factors affecting individual bereavement experiences and grief responses, many of which are embedded in the cultural mores of being a Gypsy/ Traveller. The narratives illustrate how close family relationships, protective behaviours, specific gender roles and responsibilities, poor health and distinct patterns of death shape their bereavement experiences.

The following chapter discusses each of these key themes in more detail to establish how individual bereavement experiences are influenced by cultural norms and community

practices and the extent to which membership of a close-knit family and community offers effective support for managing the processes of loss or potentially exacerbates the risk of long-term complicated grief.

Chapter 5: Discussion

Introduction

The following discussion synthesises and reflects on the extant literature considered in chapter two and the key findings of the study as detailed in the previous chapter, to consider the influences of culturally congruent bereavement practices and behaviours which exemplify how, '*who we are shapes how we grieve'* (Niemeyer 2011:412).

Niemeyer's quote above succinctly summarises how individual grief responses, although personal and unique, are influenced by personal, socio-cultural and environmental factors. These include the bereaved person's relationship to the deceased, cultural and familial behavioural expectations, personal patterns of grief and the mode of death (Asaro & Clements, 2005; Doka & Martin, 2010; Parkes, 2006; Worden, 2009). Thus individual life experiences and how these are managed will both determine personal resilience or vulnerability to bereavement (Parkes, 2011) and influence how prior experiences and cultural background entwine to influence how we grieve. Despite this presumption that it is possible, to some extent to anticipate grief reactions, no formal response can be assumed to occur although clear trends can be identified pertaining to cultural influences and common experiences.

'Whilst grief itself is not a problem, where there are complicating factors at work, the result can be serious personal and social problems that have the potential to devastate peoples lives' (Thompson, 2012:278).

The complicating factors that Thompson refers to above can result in grief shifting from a normative reaction to loss to a debilitating experience that can have a long term impact on health and wellbeing (Thompson, 2012; Van-der-Houwen et al 2010). Although grief responses are individual there are some generic factors, found in the theories and models of

grief discussed in the literature review, that determine the intensity and patterns of grief each individual experiences.

Factors affecting grief responses that determine a normative or complicated reaction are defined by Worden (2009) as 'mediators of mourning'. The key themes which impact on grief responses and the likelihood of experiencing complicated grief identified in this study can be aligned with Worden's typology as illustrated in Table Four below.

Table 4: Worden's typology and key themes

Wordens mediators of mourning	Key themes of study
Who the person was	Relationships, Personality characteristics
Attachment relationships	Relationships, children
Mode of death	Patterns of death
Historical antecedents	Patterns of death
Personality variables	Personality characteristics
Social variables	Socio-cultural characteristics – personality characteristics, patterns of death, death ritual & support
Concurrent stresses	Patterns of death, relationships , children

Although the key themes identified within this study can be aligned with Worden's (2003) mediators of mourning when situated within the context of Gypsy and Traveller culture the focus is somewhat different and must be seen in a more nuanced manner. Worden places the relationship between the deceased and the bereaved as his first mediator of mourning, and as a fundamental factor which is key to determining grief responses, whereas in this study the socio-cultural mores of being a good Gypsy/Traveller (and performing this role in a particular manner) appear to override personal bereavement experiences and grief responses. Therefore the following discussion will begin with a consideration of socio-cultural and personality characteristics to contextualise the mediators of mourning in relation to Gypsy and Traveller bereavement experiences as identified in this study.

The socio-cultural context of death

This study set out to establish the cultural norms and community practices influencing the bereavement experiences of Gypsy and Traveller families and to identify whether and how bereaved individuals are supported in both a family and community context given that death and loss are not typically openly discussed within this ethnic group, (see aims on page 4). What emerged very clearly from the data is how inextricably entwined individual bereavement experiences are within the cultural context of being a Gypsy/Traveller.

In the extant literature Walter (1999) and Niemeyer (2001; 2011) highlight the overarching role that culture and society play in determining individual bereavement behaviours, with Walter(1999) referring to the societal policing of grief to describe how bereavement behaviours and mourning rituals are influenced by socio-cultural mores. Furthermore Walter (2010:6) suggests that '*individuals are shaped but not determined by their culture'.* However for Gypsies and Travellers the prominence of cultural identity, strong cultural mores and close kinship relationships shapes the individual bereavement behaviours identified in this study as the following quotation illustrates..

'*She didn't want to let her guard down and say what she really felt, it's about wanting to protect other loved ones… you can't show your feelings you can't because you are afraid to hurt them, you have to keep a brave face on... it's part of a Traveller, it's what they do, and unfortunately that brings a lot of problems'* (focus group 1).

The example above exemplifies the strong evidence found throughout the study of how the cultural behavioural expectation of the need to protect others constrains personal feelings. This is most relevant when considering the grief responses of Gypsy and Traveller women who put other family members before themselves as a matter of course in a manner consistent with cultured and gendered role expectations. These findings agree with Stroebe and Schuts (1998) view that cultural behavioural expectations can often override personal

reactions as is evident from consideration of Thematic Map Four on page 142 which shows how significantly the cultural context of being a Gypsy/Traveller both influences and encompasses individual bereavement experiences.

Furthermore the cultural characteristics highlighted in this study align with those of Laurie & Niemeyer's (2008:177) study of African American bereavement experiences, discussed earlier in the literature review, which suggest that '*death in a close knit community is more detrimental to bereaved persons sense of self than in other cultural groups*'. This is clearly evident for the women in this study who demonstrate stoic and altruistic behaviours as the narrative from focus group one on pages 201 and 202 illustrates.

Indeed Gypsy and Traveller grief responses are reminiscent of British working class culture of grief in the late nineteenth century, where high mortality rates and poverty led to emotional restraint and grief expressed through silence and symbolic ritual (Jalland, 2013). Today death continues to remain central within the lives of Gypsies and Travellers for two reasons, firstly, the high mortality rates and frequent bereavements they experience, but also the revered and highly respected place of the dead retained through strong continuing bonds with the deceased. This is in complete contrast to mainstream Western society where the place of death has shifted from being a central and fundamental life experience to the sequestration and denial of death common throughout the early twentieth century, as a result of medicalisation moving death from home to hospital (Silverman, 2000; Walter, 1999).

Consequently there is an uncomfortable dichotomy in how death is discussed within the majority western population. On one hand death remains marginalised and an uncomfortable taboo subject in relation to personal loss, but yet it also retains a prominent place in society and public media representations and the memorialisation of significant deaths. For example through public display of large floral tributes, such as those seen following the death of Princess Diana in 1997 and more recently following the Paris and Brussels terrorist attacks, often left by people who have no personal contact with the person who has died. .

The media portrayal of (often sudden or traumatic) deaths such as those mentioned above can also increase public awareness and discourse on prominent issues related to each incident but the way in which incidents are portrayed and the prominence afforded to stories are typically related to how newsworthy a category of 'victim' is perceived to be . This is evident following the fire on a Traveller site in Carrickmine Ireland in 2015, where the tragic deaths of ten members of one extended family raised the profile of Travellers as *'hidden victims of Irelands housing crises',* as site overcrowding was suggested as a possible cause of the fire (Pavee Point, 2015). The media coverage of this incident exposed both the best and worst of Irish society. Initially sympathy and practical support was evident from both local residents and politicians who recognised the enormity of loss of both multiple family members, (including five children) and the survivor's home. This sympathetic approach was short lived as when the local council sought to provide an alternative site on council land, local residents objected to having Travellers in their neighbourhood prolonging the distress of the bereaved family and demonstrating that society's compassion for the bereaved can quickly disappear, in this case being replaced by the more common visceral prejudices Travellers are used to experiencing from mainstream populations (Joyce, 2015).

Therefore, although death surrounds us and is a universal and normative life experience, the place of death in the lives of the living is socio-culturally defined. The individualistic nature of most modern Western society keeps death at a distance, only becoming a reality following a personal loss or public tragedy, with grief denied and marginalised, yet ever present (Walter, 2010). Whereas in contrast death remains at the forefront of Gypsies' and Travellers' life experiences, impacting on them as a social group rather than individual experience with this reaction resulting from their collectivist societal structure (Liegeois 1994). Moreover socio-cultural differences also frame perceptions of death either as an ending, (as in mainstream Western society), or as a continuing spiritual journey,(as in Japanese and African American cultures), significantly influencing the place of the dead in the lives of the living (Laurie & Niemeyer, 2008; Rees,2001;Valentine, 2008a, 2009).

Walter (2010) concurs that the place of the dead is defined through socio-cultural values and beliefs. Societal values of autonomy, favoured by individualistic societies and inter-connectedness, valued by collectivist societies, will determine what communities do with the dead, i.e. let them go, retain continued bonds with them, or turn them into ancestors. Thus the continued socially understood presence of the dead amongst the living is common in many cultures and also recently recognised within Western society's theoretical approaches to loss and grief (Rosenblatt, 2013).

The collectivist culture and social structure within which Gypsies and Travellers live is an example of strong connections and continuing bonds with the dead, where the deceased retain a silent but strong voice and highly revered place in the lives of the living. This is epitomised by Williams' (2003) study of the French Manus Gypsies, entitled '*the silence of the living and voices of the dead'*, in which he suggests that not talking about the dead is a mark of respect whilst however, establishing a silence around the dead. This silence maintains culturally congruent behavioural codes and preserves the memory of the deceased without alteration, upholding reverence and respect. Similarities to Williams' (2003) findings were identified in the participant narratives of this study, where the dead remain highly respected members of the family and community and integral to the lives of the living.

'*As Travellers you are taught that they live on… to us they are not gone' 'they are in your arms they live on*' (focus group 2). Thus the dead remain interwoven with the living. Although the dead retain a central place within the lives of the living as in Williams study there is a silence created around them as illustrated in this study. The literature review explains in detail the somewhat contradictory death rituals and beliefs held by Gypsies and Travellers, where extravagant funerals and frequent visits to the graveside demonstrate respect and keep the deceased an integral part of the family. Despite these overt behaviours there is also a silence surrounding the dead as protective behaviours prevent any discussion of grief

and loss. Thus silence becomes a powerful voice (Clark et al 2013); and a response to grief, as the silence created following bereavement within Gypsy and Traveller families undoubtedly shapes the intense grief responses they experience.

Being a Gypsy/ Traveller

In order to understand the bereavement experiences of Gypsies and Travellers it is necessary to recognise the cultural mores that shape both individual and group behaviours. As illustrated in the literature review as an ethnic minority Gypsies and Travellers often live on the edge of mainstream society (Powell, 2013). This marginal physical place occupied by many Gypsies and Travellers often adds to the high levels of social, material and spatial (through restrictions on stopping places) exclusion they experience, increasing their vulnerability across all aspects of life (Convery, 2014; Ryder, Cemlyn & Acton, 2014). When this multi-factorial exclusion is added to a high rate of multi-generational premature bereavement from accidents or preventable deaths, as illustrated in table three on page 161, it means that the individual and socio- cultural significance of death remains at the forefront of the life experiences of Gypsies and Travellers (Parry et al, 2004; Richardson et al, 2007; Cemlyn et al, 2009).

It is the close knit nature of Gypsy and Traveller life which has a substantial impact on the place of death within the community. Living in a collectivist culture of close kinship based communities with relatively unchanging family structures and 'traditional' values as is common to the overwhelming majority of Gypsies and Travellers means that there is an exceptionally high level of contact between kin group members on a daily basis. This is in complete contrast to the majority of 'Western' communities where families tend to be smaller, more disparate and geographically dispersed. Thus, an individual might spend their entire life living alongside their parents and siblings, on a site, with their own children growing up, marrying and having their own family whilst living either at the same location or geographically nearby. Hence almost by definition, living in an extended family unit, the repercussions of birth and death are likely to have a greater impact and deeper resonance than for individuals who are unable to live in such close proximity to their wider family (Clarke & Greenfields, 2006). The close kinship structure of Gypsy and Traveller

communities means that the death of a relative is felt with great intensity, articulated by some research participants as an event which they '*never come to terms with'*. The significance of bereavement and loss within these groups can therefore for some people result in a continuum of loss and grief throughout the lifespan.

The stories heard during this study confirm that bereavement creates long term problems for Gypsies and Travellers, the consequences of which result from strong cognate relationships and the cultural practice of not discussing death (Okely, 1983; Williams, 2003). Embedded in these relationships are very strong protective behaviours, it is this predominant need to protect family at any cost, which results in part from living within an often hostile majority society, but also from the collectivist societal approach that favours the wellbeing of others above that of the individual that appears to have an impact on the complexity of bereavement behaviours of Gypsies and Travellers. It is particularly notable in women who will consistently put the care and protection of other family members above their own health and wellbeing.

Family is central to Gypsy and Traveller cultural identity; with very close cognate relationships providing continuity, security, and a sense of belonging that might otherwise be gained from a geographically settled or fixed abode, but that is absent from the nomadic heritage which is predicated on not having a permanent or fixed home. Thus for Gypsies and Travellers the family provides stability as a 'self-sufficient unit of mutual support' (Evans 2004: 135). Although many Gypsies and Travellers are less mobile today, with as many as two thirds of the population permanently settled in housing (Greenfields & Smith, 2010; Ryder, Cemlyn & Acton 2014), the close physical and emotional connectedness, behavioural expectations and responsibilities that put other family members needs above those of the individual remain at the forefront of Gypsy/Traveller identity.

The personal identity of Gypsies and Travellers is complex, their sense of self is embedded within the cultural ideal of '*being a good Traveller'* achieved by conforming to strict cultural

behavioural codes and not bringing 'shame' to the family for example by failing to behave in accordance with the social rules of the group. These expectations are not homogenous, but will be nuanced within and between communities. Family reputation and respect is paramount to the maintenance of the family's position within the wider community and as such underpins the social behavioural codes and pressures to behave in a culturally appropriate manner, issues which may support the collective whole but at times may be detrimental to the individual (Clarke & Greenfields 2006).

Therefore personal grief responses within this community must be considered in relation to socio-cultural mores not only cultural mourning practices and death rituals but also wider socio-cultural behaviours such as stoicism and resilience. Hence the social reality of bereavement experiences for Gypsies and Travellers is interwoven with their stoic attitudes to life where high mortality rates and bereavement experiences are normalised within the challenges and adversities of their lifestyles (Van Cleemput 2010).

Gypsies and Travellers are stoic, but are they resilient to loss?

Stoicism, the normalisation of hardship and adversity (Sellars, 2006), independence and self-reliance emerged very clearly from the data coalescing a key theme which demonstrates as a strong personal and cultural characteristic. Stoic attitudes towards illness and poor health are already identified in the extant literature, particularly those relating to the health status of Gypsies and Travellers (Atterbury, 2010; Parry, 2004; Smith & Rushton, 2013; Van-Cleemput, 2010). This study's findings concur with the literature identifying stoic attitudes to poor health outcomes, but additionally identify that stoicism also normalises the high mortality rates, frequent and multigenerational deaths that are commonplace within the community. Moreover, the findings highlight that stoic attitudes have the following outcomes:

- Stoicism is recognised as a cultural strength but is in fact a barrier to health and wellbeing.
- Stoicism normalises adverse life experiences such as poor health, patterns of death and frequent bereavements.
- Stoic, independent and self-reliant behaviours constrain the expression of emotion through prioritising protective behaviours.

'Travellers are quite stoic', this statement was frequently repeated throughout the study with the majority of participants talking about being strong and stoic, with many stating that they did not have time to grieve, but '*just had to get on with it'*. Stoicism and strength of character, often demonstrated through the need to be self–reliant was a consistent theme throughout the study and attributed to the adversity of their lifestyles, the challenges of cultural survival and separateness of their lifestyles in comparison to the mainstream population ((Evans, 1999; Liegeois, 2005; Richardson et al, 2007). Whilst maintaining this separateness protects their cultural heritage it has resulted in public displays of stoicism becoming a strong feature of Gypsy and Traveller identity and a characteristic which individuals aspire to and take pride in (Parry 2004; Atterbury, 2010; Smith & Rushton, 2013). Autonomy and self-reliance are important aspects of both personal and social identity often demonstrated through stoic attitudes, as noted above, of *'just getting on with it'.* However whilst this stoic approach to life, of not giving in to adversity, is seen as a cultural strength it can clearly have a detrimental effect on health and wellbeing, for example leading to a refusal to r recognise ill health even when easily treatable (Van Cleemput, 2010) and an acceptance of the community's negative life experiences as inevitable rather than preventable.

Many, negative impacts such as high maternal mortality rates could be avoided with better health interventions (Reid, 2005; Bhaji & Salway, 2008; Matthews, 2008). However a combination of prior poor experiences impacting on trust and Gypsy and Traveller separatist and protective behaviours and practices, mean that ill health and high mortality rates are

normalised, yet feared within their own cultural experiences, with a widespread consequential lack of awareness of their community's differences in health and mortality rates compared to the mainstream population. The quotation below exemplifies the impact of such limited health literacy and knowledge of mainstream health trends.

"Tragic, no one questioned the loss the amount of children, we didn't realise how many more Traveller children died" [than the majority population] (narrative G).

Not only do these stoic attitudes result in an acceptance of high morbidity, frequent and multiple bereavements within short periods of time, *'We've had five bereavements in just nineteen months, that's five in the family'* (narrative I), but also results in a fatalist approach towards the frequent deaths experienced, many of which may be preventable with better health care.

The complexity of bereavement behaviours within Gypsy and Traveller communities may be attributed to some extent to their stoicism as in fact, grief has been found to be more intense in stoic individuals and families than in families who openly expressed emotions with each other (Traylor, et al 2003). Moreover Allen (2007) suggests that stoicism in relation to bereavement behaviours is more prevalent in lower socio economic groups. Howarth (2007a) concurs asserting that working class stoicism in relation to bereavement is linked to the lifestyle challenges and adversities faced by the lower socio economic groups, suggesting that there is little time to grieve whilst managing the material hardships of their life experiences in comparison to those with higher socio economic status.

The findings of this study concur with those of Allen (2007) and Howarth (2007a). Gypsies and Travellers are amongst the most deprived groups within the lower socio economic category (Cemlyn et al, 2009; Ryder & Greenfields, 2012; Equality and Human Rights Commission (EHRC), 2015) and as such as much as being stoic is an attribute that Gypsies and Travellers take pride in and aspire to (Van Cleemput 2010; Smith & Rushton, 2013)

stoicism appears to have a negative impact on bereavement and the expression of grief as exemplified below:

'We do expect a lot of ourselves we have to cope with everything, to carry on with family life; you almost haven't got time to grieve' (narrative B).

Stoicism normalises hardship and adversity as inevitable (Sellars, 2006) whereas resilience, the other side of the coin concerns an individual's capacity to overcome adversity (Cyrulnik, 2009; Masten, 2014, 2014a; Reich et al, 2010; Rutter, 1981, 1999, 2012; Walsh 2003). Whist stoicism is an undeniably strong characteristic within Gypsy and Traveller culture consideration also needs to be given to their resilient attributes as well to ascertain if bereavement behaviours are underpinned by stoicism or resilience.

Throughout the research participants referred to stoic attributes rather than resilience. Interestingly just one narrative mentioned resilience, suggesting that it has been lost through the erosion of cultural heritage.

'I think in earlier times the travelling community had a resilience and survival skills where the older person would have the knowledge and relate it to the younger person…but today I think it has been lost… the culture and language is lost' (focus group 1).

If resilience is defined as relating to an individual's capacity to recover from adverse life experiences including trauma and high levels of stress, then bereavement falls within this definition (Daniel & Wassel, 2002; Reich et al, 2010; Rutter, 1981). Defined as *'a woven web of relationships and experiences over the life course and across generations'* (Walsh, 2006:12), resilience is influenced by both family and environmental factors, each of which create either a positive buffer or increased risk or vulnerability to the development of resilience. Rutter (1981) identifies a number of domains (both personal and environmental), by which individual capacities for resilience can be measured against the dominance of risk and protective factors within each person's life. Personal domains include personality traits

and gender, capacity to cope with stress factors, change and family influences, whilst environmental factors include living conditions. It is impossible to separate personal and environmental factors where Gypsies and Travellers are concerned, as their nomadic traditions are increasingly compromised and an insecure living environment may be a significant cause of stress, with fear of eviction, prejudice and persecution common concerns amongst research participants. In addition, poor and dangerous living environments account for a number of intergenerational sudden unexpected deaths such as those associated with traffic accidents or poor environmental health. Negative family circumstance can also result from accommodation change with families being 'broken up' and unable to live in the close proximity that they are used to. In addition, bereavement will also have a significant effect on family with changing roles and responsibilities (Richardson et al, 2007; Cemlyn et al, 2009; Smith & Rushton, 2013). Thus, whilst the closeness of family is a strong protective factor associated with resilience, changes in circumstances such as those outlined above can also create additional stress factors.

Rutter's (1981) consideration of personality traits and gender roles is particularly pertinent to Gypsy and Traveller families as he highlights psycho-social stressors in male patients, particularly those linked to family discord, proposing that males are more vulnerable and less resilient than females to stress. Evidence of male responses to family bereavement stressors within Gypsy and Traveller families in this study repeatedly note high incidences of risk taking behaviours and bereavement-related suicide; supporting Rutter's proposition of increased male vulnerability. In contrast Gypsy and Traveller women are often responsible for keeping the family together and demonstrate a stoic or resilient attitude as this narrative extract elucidates:

'More men than women [commit suicide] as they can't cope with [it] and take their lives, most of the men do take their own lives but the women seem to think they have to get on with it' (focus group 1).

Overall, whilst positively correlated resilience markers are clearly found within Gypsy and Traveller culture and traditional family structures: (predominantly secure emotional attachments, strong relationships; the availability of emotional support; security, and a structured family environment with clear and consistent boundaries all of which were noted by respondents as fundamental to Gypsy and Traveller values) the overriding cultural need articulated throughout the narratives to *'protect family at all cost'* may, as normatively practised, be detrimental to developing personal support and resilience.

Although protective behaviours may thus appear to create individual vulnerability rather than resilience when applying Walsh's (2011) family resilience framework, (discussed in the literature review), to Gypsy and Traveller families it is evident that they exhibit many positive resilience factors, such as strong cultural and religious belief systems, close kinship family relationships and strong community social networks. Nonetheless Mancini and Bonanno (2009) assert that the presence of positive resilience characteristics does not necessarily translate into resilient behaviours following stressful situations across the lifespan.

Although not conclusive there is some evidence that confirms the coexistence of resilience and vulnerability in those that have experienced trauma earlier in life (Greene 2010; Shirira et al, 2010, 2011, 2011a). For example Holocaust survivors with community support were usually resilient in most physical domains but demonstrated psycho-social vulnerabilities, in particular depression and PTSD. Similar patterns were found in comparator groups of older people who had experienced trauma earlier in their lives, as was an increased vulnerability to loss with age (Shirira et al, 2011).

The study's findings clearly suggest that there is a coexistence of both resilience and vulnerability across different functional domains. Thus although there is some evidence of resilience within family and community contexts this is not evident in individual bereavement behaviours confirming Mancini and Bonanno's (2009) standpoint that the presence of resilient characteristics does not always result in resilient outcomes in all situations. For

example when considering resilience to loss the positive resilience factors identified earlier are juxtaposed against culturally protective behaviours that increase vulnerability and inhibit communication and emotional openness. This suggests that whilst there are strong elements of family resilience in some, mostly physical domains, such as in the maintenance of cultural mores, Gypsy/Traveller identity and strong social capital, the overriding need by individual family members to protect each other results in a physical closeness but emotional distance, creating vulnerability rather than resilience for individual family members. This is particularly evident when faced with multiple intergenerational bereavement and loss where protective family relationships result in psycho-social vulnerability and a lack of inter-generational resilience. Nonetheless whilst individual family members appear to be vulnerable rather than resilient to bereavement and loss the culturally mediated behaviours which favour the collective family and community structures within which Gypsies and Travellers live do offer family and community resilience and a sense of identity

Resilience is increasing being considered an important factor in determining the adjustment to loss following bereavement (Bonanno, 2008; Niemeyer, 2011; Mancini & Bonanno, 2009, 2011; Walsh, 2011). Bonanno (2008:102) considers resilience to loss as being able to *'maintain a stable equilibrium'* or continue to function normally following loss; conversely those who have difficulty recovering from loss are often less resilient (Mancini & Bonanno, 2011).

Worden's (2009) mediators of mourning are also influential in determining resilience to loss, the relationship with the deceased and circumstances of death are particularly likely to impact on resilience. The loss of a child, sudden and traumatic modes of death and being a carer during long term illness or palliative care can significantly reduce resilience to loss (Boerner & Jopp, 2010). Furthermore resilience to loss appears to diminish with age as loss becomes more frequent. Not just bereavement losses but the loss of health and resources also increases with age exacerbating the impacts of bereavement. .

'When you're older, when you have lived your life, the sadness stays with you' (narrative I)

Whilst Gypsy and Traveller women may outwardly appear to be *'getting on with it'* perhaps even demonstrating resilience to loss by continuing with daily routines and giving little evidence of their grief. The reality is that rather than maintaining equilibrium and demonstrating resilience as Bonanno (2008) suggests it is often their stoicism that gives an outward appearance of resilience and coping. In fact grief is internalised as a result of the culturally mediated protective behaviours, often leading to complicated grief reactions characterised by long term distress depression and poor health. Evidence of the long term impacts of grief on the health and wellbeing of the respondents were summarised by stating that *'bereavement can go on for ten to fifteen years'* and that they '*never come to terms with*' their losses.

Despite this family and community resilience is evident particularly in physical domains, drawn from close family and community support mechanisms, strong cultural mores and religious belief. However, the frequency of bereavement and loss normalised by fatalist stoic attitudes often has a debilitating effect on individual resilience to loss. The desire of respondents to protect family members through not talking about the deceased person and their stoic and altruistic attitudes may be detrimental to individual emotional resilience; as grief is internalised. Hence the desire to alleviate grief, and the culturally accepted way of protecting family members from pain by avoiding the subject of death and loss is so strong that it seems to create personal vulnerability rather than increase emotional protection for some individuals (Rogers 2015).

Gender, women cry and men carry on

'I'm not saying men don't' feel the same, as much as women, but they seem to get over it quickly' (focus group 1).

The narrative above summarises the gender differentiated patterns of grief and responses to bereavement which have been highlighted throughout the study as gender emerged as an influential feature of this research. The findings suggest that distinct gender roles and responsibilities remain prominent in Gypsy and Traveller culture, leading to the following outcomes.

- Gendered responses to bereavement align with Doka & Martin's (2010) patterns of grief, asserting that women are more likely to be affective grievers and men instrumental.
- Cultural expectations of gender roles define bereavement behaviours and expressions of grief.
- Strict moral codes surrounding gendered behaviours create communication barriers between men and women and constrain the expression of emotion.
- Gendered behavioural expectations and protective practices hinder the expression of grief.
- Women overlook their own health and wellbeing, expressing feelings of '*not being worthy of grieving'.*

Gender roles and responsibilities within Gypsy and Traveller communities are somewhat reminiscent of traditional historic roles. Outwardly Gypsy and Traveller men are the head of the family and in public women often appear submissive to men, whereas in private there is a more equal relationship. Nonetheless, a clearly defined gendered division of roles and responsibilities remains core to Gypsy and Traveller culture. As 'Head of the Family' men will be responsible for maintaining family honour and respect, (values that underpin Gypsy and

Traveller behavioural codes), and for supporting the family practically and financially, whilst women have domestic responsibilities for maintaining the home, caring for children and the elderly (Acton, 1997; Clark & Greenfields, 2006). The role of Gypsy and Traveller women is complex and contains strict moral codes that are embedded in cultural beliefs and traditions based on the concepts of purity and pollution. These concepts are also overwhelmingly linked to taboos and beliefs relating to the extent and degree of contact with the mainstream population (Gorgios), preventing acculturation and assimilation into the majority society by maintaining cultural boundaries through ritual practices associated with hygiene and cleanliness. Purity and pollution are represented by distinctions made between the inside and outside of the body; the outer body providing a symbolic or external representation of the Gypsy Traveller that is presented to the outside world, whilst the inner body represents purity and the true ethnic self (Okely,1983). These concepts of purity and pollution are particularly pertinent to women as female sexuality and childbirth are seen as potentially polluting towards men and as such many of the behaviours, roles and responsibilities of women have their foundations in these taboos and beliefs (Acton, 1997; Liegeois, 2005).

Furthermore the cultural role and responsibilities of women in charge of domestic life means that, as seen from the narratives in the previous chapter, they are characteristically stoical with a strong sense of responsibility and of '*being able to cope'* with whatever life experiences they encounter however traumatic The consequences of the complex and challenging roles of Gypsy and Traveller women are that personal wellbeing becomes secondary to the roles of wife, mother, and carer. This was exemplified by the majority of participants in focus group one, stating that:

'You are not looking for care for yourself and that's a big issue with [women] Travellers they feel that they are not worthy of that".

These findings echo those of Hodgins et al (2006) who found that Gypsy and Traveller women compromise their own health in favour of family responsibilities, and those of Kotze

et al's (2012:751) research with bereaved Black South African women who suggests that '*Women's lives and identities are interwoven with the lives of their communities*'. Similarly the Gypsy/ Traveller women in this study appear to find their self-identity embedded in and defined by cultural and gender role expectations of being a Gypsy/Traveller woman. The outcome of this aligns with the suggestion of Field (1997:6) that *'women bear the brunt of the taboo of death both as carers and as victims of bereavement'.*

The gender orientated roles and behaviours discussed here are reinforced in the literature review which confirms that socio-cultural structures and gender roles regulate the life experiences of men and women (Warwick-Booth, 2013), including bereavement behaviours and patterns of grief. The bereavement behaviours noted in this study are reflective of Doka and Martins (2010) gender based patterns of grief whereby men generally show instrumental patterns of grief and women more affective grief responses. This is evident in the stories shared in the previous chapter proving that the behavioural expectation of men conforms to male stereotype of being strong, stoic and silent. However for women cultural mores are contradictory, whilst the expression of grief is acceptable within certain boundaries the complexities of their roles and responsibilities and the strong protective behaviours override personal grief responses as illustrated in the preceding discussion.

Furthermore whilst men will often remain silent, not talking about loss and using alcohol as a coping strategy, women are more likely to express emotional distress and experience anxiety and depression (Fried et al 2015; Stroebe & Schut 2001; Van-der Houwen, 2010). These coping strategies are evident in the stories shared in the previous chapter. The frequency of death and loss and socio-cultural pressure of maintaining these behavioural expectations appears to underpin some of the physical and mental health problems that are prevalent within Gypsy and Traveller communities.

Patterns of death

The patterns of death highlighted by this research clearly identify the inequalities between Gypsies and Travellers and the mainstream population. Although this is not a comparative study the stark differences, particularly in maternal health and infant deaths discussed in the literature review and highlighted in the patterns of death identified in this research cannot be ignored, but are in fact pivotal to understanding the bereavement experiences of this ethnic minority people.

Key findings:

- The findings concur with both the extant literature and anecdotal evidence suggesting high numbers of premature intergenerational death.
- Modes of death are mainly sudden, traumatic and in some cases potentially preventable.
- The frequency of sudden and traumatic loss often results in complicated grief responses.
- Miscarriage and stillbirths are significant losses and occur at a far greater rate than found in surrounding mainstream populations. .
- High incidences of suicide

It is well attested that the health status of Gypsies and Travellers is '*significantly poorer*' than the mainstream population (Parry et al, 2004:1). Parry and her team's seminal study on the health status of Gypsies and Travellers remains the most noteworthy and robust in the UK, despite now being over ten years old. Sadly little improvement seems to have been made since Parry et al's research took place as the 2011 census findings confirm that Gypsies and Travellers have the lowest self-disclosing rating of good health at 70% in comparison to 81% of the majority population and only 6% of the Gypsy/Traveller population are reportedly over the age of sixty-five (ONS,2014a). These poor health outcomes continue to be

attributed to inappropriate accommodation and lack of access to services, with those living on unauthorised sites and at the roadside experiencing the poorest health outcomes (Greenfields & Brindley, 2016).

These health status outcomes are inextricably linked to low life expectancy and high mortality rates reported throughout the literature review and most recently in Greenfields and Brindley (2016) study for the Department of Health and the latest EHRC (2015) reports. The patterns of death identified in Table Three on page161 reinforces these findings highlighting specific modes of death, including high prevalence of suicide, miscarriage and stillbirths many of which are potentially preventable with appropriate and timely interventions.

Whilst statistics for infant mortality continue to decline year on year in the UK resulting from better medical care and public health services, those in the lower socio economic status groups continue to experience the greatest deprivation, a factor which is closely linked to the highest infant mortality rates.

Infant mortality is related to maternal deprivation, and is 1.6% higher in the lower socio economic groups than the highest socio economic group, whilst 24% of these deaths are potentially preventable (Oakley et al, 2009; ONS, 2015). This pattern is significant to this study as Gypsy and Traveller are some of most deprived and socially isolated ethnic minorities in the UK and thus at particularly high risk of experiencing infant mortality, whilst similar trends in relation to the excessive prevalence of maternal mortality amongst these groups are also well documented (Communities & Local Government, 2012; Hudson, 2009; Greenfields & Brindley, 2016).

The stories highlighted in the previous chapter illustrate the challenges that Gypsy and Traveller women face difficulties accessing maternal health care and the serious health risks associated with these; resulting in the intergenerational continuation of poor maternal health and disproportionately high numbers of stillbirths and miscarriage.

Similarly the high suicide rates discussed earlier were found to be a prevalent mode of death in this research. As noted in the literature review Werthheimer (2001) has written about the 'ripple effect' and far reaching consequences of suicide for the bereaved, this ripple effect is exemplified by the narrative on p170, where the family experienced three suicides in close succession including bereavement suicide as the father committed suicide whilst in a state of grief following the suicide of his daughter. Bereavement suicide is further endorsement of the potentially devastating impact of engaging with extreme coping strategies used as a result of the culturally protective behaviours that prevent the discussion of grief and loss.

Relationships

'Death ends life but not relationships' (Walsh & McGoldrick, 2013:21), for grieving families this statement succinctly summarises the challenges of bereavement, coming to terms with the loss of a loved one and adapting to change associated with the loss. Walsh and McGoldrick's (2013) quote is pertinent to current continuing bond theories, recognising that significant relationships continue after death, through the transference of relationships from a physical presence to an internal relationship or continuing bond through spiritual connections, kinship networks and memories (Klass, Silverman & Nickman, 1996).

The relationship between the bereaved and the deceased is fundamental to grief theory and to shaping individual grief responses. Worden's (2009) first two mediators of mourning refer to the relationships between the bereaved and the deceased, considering who the person was and the strength of the attachment relationship between them. Thus those bereaved of a close family relationship, such as the loss of a spouse or child are likely to feel the loss more intensely than when bereaved of a distant family member or friend, making the relationship between the deceased and the survivor pivotal to grief responses (Bowlby, 1980, 1981; Parkes, 2006).

Attachment theory has become a widely used theoretical framework to understand the differing severity of grief responses that the bereaved experience (Delespaux et al, 2013; Parkes, 2006). Bowlby (1981) suggests that the stronger the attachment to the deceased the greater intensity of grief, thus those with securely attached relationships are most likely to experience the most intense grief reactions (Wayment & Vierthaler, 2002). Although secure attachments result in a stronger expression of grief securely attached individuals are less prone to depression and somatic grief reactions. Whereas those with anxious (evident through separation anxiety, feelings of abandonment and excessive emotionality), or avoidant (demonstrable through emotional avoidance and strong independent traits), attachment relationships are more likely to be vulnerable to complicated grief responses and higher levels of depression and somatic reactions (Delespaux et al, 2013; Stroebe, 2002).

Bowlby's (1981) suggestion that secure attachments create the most severe grief responses are validated through the intensity of grief identified in the bereavement experiences of Gypsies and Travellers. Whilst strong secure attachments may account for the intensity of grief responses found in bereaved Gypsies and Travellers the high levels of depression and complicated grief response are most likely attributed to other influences such as the frequency of bereavement and loss and complexities of their lifestyles.

Attachment theory highlights the importance of family in providing stability and security, influencing both early childhood attachment relationships and the patterns of grief experienced following bereavement and loss (Bowlby, 1981; Parkes, 2006, 2010). Thus family is pivotal to the formation and maintenance of attachment relationships both in life and following death.

Although current models of grief recognise the individuality of grief responses, bereavement and grief cannot be considered purely on an individual basis as individuals are defined by their interdependent relationships with others, usually within a family context (Hayslip & Page, 2013; Moos, 1995). If grief is only considered from an individual perspective the wider

context and impact of family may be overlooked (Rosenblatt, 2013). Thus grief occurs on multiple levels as individual patterns of grief are embedded within family systems and relationships (Walsh & McGoldrick, 2013). Moreover the extent to which families provide either support for, or barriers to individual grief responses is determined by the functional effectiveness of the family. How effectively family systems work is influenced not only by cultural values and beliefs but also from the ecological context of how individual families interact with the socio-cultural environment within which they live (McCubbin & McCubbin, 2012).

The sphere of influence diagram (Figure 6 on p146) illustrates how the individual is situated within the family and wider socio-cultural support networks. The diagram portrays the factors affecting individual bereavement experiences of Gypsies and Travellers from an ecological perspective. In this instance the individual is embedded within the close knit collectivist family structures. Interdependent family relationships mean that grief and loss affects each family member differently both on intrapersonal and interpersonal levels. Individual grief responses affect physical and mental health and wellbeing and interpersonal family relationships impact on social outcomes. Therefore family systems and relationships are fundamental to individual grief responses (Hayslip & Page, 2013). Just as the individual is nested within and supported by the family system, families gain support from being embedded within a wider community structure. For Gypsies and Travellers this support comes from the kinship and community networks, strong religious beliefs and living in close geographical proximity to each other. However being an ethnic minority group who often live on the margins of the mainstream society, engaging in the next tier of an ecological support mechanism (with wider society) can be challenging with barriers to accessing universal service provision (Smith & Ruston,2013l). Hence family and community support are pivotal to these communities who may be unable to draw upon other systems which many of us take for granted. .

The importance and influence of family as a core support system is evident in the findings of this study as 'family' emerged as an overarching theme highlighting the following elements: :

- Gypsies and Travellers have close and complex family relationships.
- Relationships are defined by cultural mores, gender roles, responsibilities and generational conventions which create barriers to communication and the expression of grief.
- Close physical relationships, but an emotional distance in relation to bereavement and loss.

Although there is clear evidence of close family relationships, *'Travellers are a lot closer to their families and I think it's a cultural thing'* (focus group 2), the extended family structures within which Gypsies and Travellers live appear to complicate individual grief responses and bereavement experiences. Thus despite the close kinship relationships that might suggest supportive family structures, strong protective behaviours also create barriers between family members minimising the effectiveness of support, a situation summarised in the statement that *'bereavement separates families'* (narrative C).

Throughout this study the participant narratives highlight the complexities of their family structures and relationships, none more so than B's story (see Appendix One) which exemplifies the personal conflicts that arise whilst trying to protect other family members and maintain cultural mores and behavioural expectations. Similarly G's story (see page 181) illustrates the long-term impact that the protective behaviours and the silence this creates can have on a family. In this latter example the silence created following the stillbirth of her baby lasted for decades, isolating each family member within their grief.

Worden (2003:32) suggests that *'In any bereavement it is seldom clear what has been lost*' obviously, the death of a significant person results in the loss of an immediate family

relationship, husband, wife, mother etc. but in addition the role and function of the deceased within the family will also have a wider impact, creating relational changes to family functioning and dynamics. For Gypsies and Travellers bereavement may accordingly appear to result in the loss of family cohesion, as whilst there is a strong physical cohesive presence, protective behaviours limit emotional support.

Moreover the high mortality rates and low life expectancy mean that often the bereaved find themselves thrust into new roles without the support of older role models. The reorganisation of family systems through changing roles and responsibilities alongside adversities of their lifestyles often means little or no time for adjustment to new roles. These changes can be particularly challenging for women. Greenfields and Brindley (2016) suggest that 42% of Gypsy and Traveller women have significant responsibilities as carers, leaving little opportunity for them to grieve or gain support following bereavement as they support the family. Parkes (2010) discusses the hierarchy of need for care and support, questioning who provides support for those at the top of hierarchy. For many in the majority population the answer would be bereavement support services. However as this research has identified for Gypsy and Traveller women cultural mores and protective behaviours prevent open communication and bereavement support within their family and community and as previously discussed they are less likely to access universal service provision (Greenfields, 2008; Matthews, 2008 Peters et al, 2009; Smith & Rushton, 2013). Further insight into the bereavement support needs of Gypsies and Travellers is discussed in the section on support later in this chapter.

As illustrated throughout the literature and research findings and considered extensively above relationships within Gypsy and Traveller families are complex, hierarchical and governed by their strong cultural mores and distinct gender role behavioural expectations. Notwithstanding this any discussion on family relationships would not be complete without considering how family bereavement affects children.

Children and bereavement

Many factors that influence the resilience and wellbeing of adults have their roots in childhood, with the role of parents and families a consistent factor in shaping the outcomes for children and the life chances of the adults they become (Field, 2010). Life chances begin to be determined during pregnancy and are influenced further by family background and circumstances including the social position, health status and educational attainment of parents and carers (Marmot, 2010). Consequently poor early childhood experiences result in placing children on trajectories of disadvantage across their life course (Allen, 2011; Lemer, 2013).

Children who experience grief early in life within a supportive environment of adults who provide them with explanations and understanding will have the capacity to cope with grief and loss in life and will develop emotional strength and resilience, as family support provides a buffer for traumatic experiences (Munroe & Kraus, 2010). However if childhood grief is not acknowledged and supported it can become a risk factor potentially leading to complicated grief and mental health problems in later life. Therefore it is essential to consider the impact of bereavement on children to be able to support and develop emotional resilience into adulthood (Akerman & Stratham, 2014; Lemer, 2013).

Children's understanding of death is often underestimated as their behaviour repeatedly fluctuates between periods of sadness and normative behaviour giving the appearance that they only grieve for a short period of time. In fact children 'puddle jump' dipping in and out of their grief as a coping strategy for understanding and managing their loss. This oscillation of behaviour fits Stroebe and Schuts' (1998) dual process loss and restoration model of bereavement whereby the bereaved individual shifts back and forth from a loss orientated approach focusing on the grief and trying to understand the loss, to a restoration orientation focused on the adaptation to change and life without the deceased. For children this process of grief, loss and restoration can continue throughout childhood and adolescence as the

understanding of loss and death involves the interplay of developmental phases and experiences during which the permanence of the death and loss evolves with increasing cognitive understanding.

For example the common belief of Gypsies and Travellers is that children are too young to understand death unfortunately the practice of not discussing the deceased is contradictory to the needs of bereaved children, as both background literature on childhood bereavement in mainstream communities and this research revealed children need to have their grief acknowledged thoroughly by being able to express their feelings and talk about their loss. Having friends and someone to talk to and to be able to talk about the person who had died was the overriding message from the children participating in this study. It was particularly important for them to be able to talk about and remember the person they had lost and whilst there was a strong acknowledgement of the sadness of loss for the children it was also essential to *"remember the good things about the person who has died*", remembering the positive and *'happy'* things they had done with the deceased not just the sadness of their loss (Children's workshop).

Being able to talk about the deceased is important as it provides a strong foundation for the development of a resilient mind set, in particular being able to talk about the deceased in a positive and meaningful way helps to adapt attachment relationships and to develop and maintain a continuing bond with the deceased (Klass, Silverman & Nickman, 1996). However given the cultural behaviours and protective practice of not discussing grief and loss Gypsy and Traveller children's needs of expressing their grief, discussing feelings and the person they have lost does not generally happen. This means that bereaved Gypsy and Traveller children are potentially not receiving the emotional support necessary for them to manage their grief effectively so as to develop resilience and emotional wellbeing. The results of the children's workshop align with Silverman and Wordens (1992) suggestion of children's needs following bereavement, most significantly the need to have opportunities to

remember and talk about the deceased, something that is currently missing within Gypsy and Traveller communities as a result of protective behaviours and strong cultural practice which preclude discussing death. Thus a lack of explanations for children pertaining to death and loss leaves them with incomplete stories and an awareness of change but without understanding why (Munroe & Kraus, 2010).

Children's outcomes following bereavement are strongly aligned with parental mental health and the quality of familial support they receive (Fauth, 2009; Ansley- Green et al, 2011). The inclusion of children in many life experiences including death rituals as is common in Gypsy and Traveller communities can have positive outcomes. For example Dyregrov (1996) advocates that participation in death rituals can aid the process of grief, whilst Rutter (1981) notes that participation in major life events acts as preparation for later life experiences. The philosophy and approach that children learn from experiencing inclusion in life events underpins how Gypsies and Travellers bring up their children, and was evident throughout the research with participants confirming that '*get their questions answered just by being there'* (focus group 2). Notwithstanding that inclusion within death rituals can be a positive experience which supports the grief process; this can only happen if children are well supported emotionally and given explanations to aid their understanding of what they are experiencing. Unfortunately this does not seem to happen as part of Gypsy and Traveller children's experiences as this extract from focus group one confirms, '*they wear the hat of what is going on but we don't explain anything to them'.* The lack of explanation and general consensus in the research findings '*that children are too young to understand'* means that children do not appear to receive the emotional support necessary to understand their physical experiences of involvement in death rituals.

Hence the long term impacts of early childhood experiences noted in chapter four may well be the result of not having effective bereavement support as children.

Following bereavement the world view of children changes dramatically, influenced by their age and developmental understanding of death and the support they receive from family. The research findings from this thesis suggest that whilst family and community provide protection and physical care for children, the cultural focus on physical support and protective behaviours that mean death and grief are not openly discussed means that both children and adults lack emotional support following bereavement.

The findings of this study have identified a need for specialist bereavement support services for Gypsy and Traveller adults; but children may also benefit from external support services to enable them to explore their feelings and emotional responses openly. However despite universal child bereavement support organisations such as Child Bereavement UK and Winston's Wish being available the articulated general hesitance of Gypsies and Travellers to use universal services means that culturally specific support for both children and adults are required, (see recommendations page 227).

Support for children which fulfils the three key elements articulated in the quote below are essential, enabling children to grieve effectively, grow around their grief into resilient adults with stable mental health and wellbeing and be supported in remembering their loved ones whilst drawing comfort from continuing bonds with the deceased.

'Children need to be given hope for their future so that they feel resilient in the present and can take comfort from the past' (Stokes, 2004).

Support

The theme of support sits at the bottom of Thematic Map Four (page 142) but draws all of the other themes together underpinning ways of diminishing negative impacts of bereavement experiences. The example below illustrates the diversity and individuality of both support needs and the availability of support for Gypsy and Traveller communities.

'We're not even talking about different community, you're talking about different bits of the community, someone on a site will have a lot more support than someone in a house and someone on the roadside is going to have nothing at all. And you have some people that like to talk and some don't and if you're somewhere with no-one to talk to you can feel even more desolate if you are someone who likes to talk to. Sometimes talking to someone very close to you like your wife or husband can be the hardest thing to do in the end and some can find it very easy, it's not like every shoe fits' (focus group 2).

The analogy of shoes fitting is interesting and can be related to the quote from Richardson et al (2007) in the literature review on page 81 that refers to the changing roles and responsibilities of Gypsy and Traveller women following bereavement. As illustrated throughout the thesis the stoic and altruistic characteristics as core to Gypsy and Traveller women's identity means that they put the needs of their families before themselves.

Furthermore as noted in the previous chapter the research findings highlight that when participants discussed or referred to support from family and community the focus was on physical support, as highlighted in the example from focus group one on page 184. The emphasis on practical support following bereavement aligns with Laurie and Niemeyer's (2008) research on African American bereavement experiences, discussed in the literature review, which found that in close kinship communities practical support following bereavement accentuated stoic attitudes and an inward facing approach to the management of loss. However whilst strong community support is evident in the findings of this study, the participants noted the increasing challenges of maintaining this mode as lifestyle and accommodation patterns change, and families do not always live in as close proximity as in the past. Whilst family and community were identified as providing support close kinship relationships were also highlighted as a barrier to overcoming grief. Some participants noted that seeking support, particularly external support, could be perceived as a sign of weakness, and of not being able to cope, contradicting the cultural norms and behavioural

expectations that favour stoicism. In addition there were concerns about confidentiality of information shared within a community where everyone knows each other. There were concerns raised about how information may be used in the event of conflict either within or amongst families, thus suggesting an insight and rationale for the value placed on privacy and protective behaviours highlighted within the research.

The emphasis placed on the physical support provided by kin and community following bereavement and protective behaviours that hinder open communication and discussion of grief and loss clearly suggest a gap in the ability of family and community to fulfil emotional support needs.

Furthermore the findings of the research recognised that there was a need for additional support to be provided with universal agreement from the participants that specialist culturally competent bereavement support services were needed. Despite this acknowledgement, only one of the participants had accessed an external bereavement service and whilst others recognised that accessing support might have been helpful in the past they stated that they did not currently need any support as they were *'coping'* with their losses. This was an interesting outcome reinforcing Van Cleemput's (2000) and Smith and Rushton's (2013) findings of deep rooted reluctance to access external services, highlighting the stoic nature of Gypsy and Traveller women and acceptance of their life experiences, but also the need for specific rather than generic support programmes and supporting Rushton and Smith (2013), Smith and Rushton (2013); Van Cleemput (2010) and Richardson et al's (2007) anecdotal evidence which notes a lack of culturally acceptable support options following bereavement.

The outcomes of the initial scoping exercise with external bereavement support agencies further reinforce the lack of engagement of services with Gypsies and Travellers (see appendix four for summary of responses). Moreover where support has been provided it is as a result of an already established and trusted relationship which creates a gateway for

bereaved community members to seek services. The development of mutual trust is fundamental given the recognition of the need for confidentiality and privacy of information. This ensures that cultural behavioural expectations and family respect are maintained. The narrative examples in the previous chapter highlight the dichotomy in participant responses regarding who should provide external support services; mainstream service providers or Gypsy/Traveller support workers. Nonetheless whilst there is some discrepancy about who should provide specialist bereavement support services for Gypsies and Travellers the need for additional support was overwhelmingly validated by both Gypsy/Traveller participants and external service providers.

In the absence of the use of formal bereavement support services the following discussion considers the place of death ritual and religion as support mechanisms.

Ritual and Religion

The place of religion both as a societal and bereavement support network has diminished within mainstream Western society (Rees, 2001; Dillon, 2010), but remains fundamental to Gypsy and Traveller death rites particularly for Irish Travellers who maintain strong Roman Catholic beliefs. Strong religious belief was evident in the responses from the Irish Traveller participants threading through their stories and highlighted as an important part of their identity. For these participants religion offers support combined with strong links to continuing bonds with the deceased. Valentine (2008a) suggests an alignment between a continuing bonds philosophy and beliefs around spirituality and resurrection common to Roman Catholics. In this research religious support often links to providing a place for the deceased with references made to the deceased being in heaven or *'going to a better place'*. Similarly the example from focus group one on page 173 also emphasises how religious support networks provided a physical representation of loss in the form of a rose garden dedicated to memorialise the loss of a baby through miscarriage.it is noteworthy however, that although Irish Travellers made reference to their religious beliefs about the deceased

being in heaven and attending mass no further specific references were made to individual ongoing support received from the church or clergy following funeral rites.

Religion and rituals appear to offer support by providing a physical place, usually the graveside or as seen above a memorial rose garden, as a physical space to represent the deceased, somewhere to maintain the continuing bond with the dead person whilst demonstrating the reverence and respect afforded to the deceased. The importance of ritual practices, as identified in the previous chapter, were the same across both English Gypsy and Irish Traveller participants; however the English Gypsies referred to traditions and the Irish Travellers more often to religious practices. Whilst these were essentially the same and included the practices of sitting up and holding wakes the origins as Gypsy/Traveller traditions or religious practices were unclear whether emerging from organised religious practice or cultural tradition. Either way the important factor is that these ritual practices offer a form of support following bereavement.

Defining the concept of support is somewhat subjective; a reminder that is restated in the previous chapter recognising that the researcher's perspective and that of the participants may differ. The researcher's perspective is broad considering the theoretical concepts that necessitate both emotional and practical support needs following bereavement. The theme of support identified by the research participants has however a much greater focus on support from a practical perspective but still recognised the need for more emotional support. Nonetheless the research suggests the close cognate family does not offer sufficient emotional support following bereavement as protective behaviours create silence and barriers isolating individuals and complicating grief responses.

Strengths and limitations of the research

The stories told in this research confirm that bereavement has a significant and long term impact on the health and wellbeing of English Gypsies and Irish Travellers, validating the anecdotal evidence found in earlier research studies on health and accommodation, such as Parry et al (2004) and Richardson et al (2007).

The strengths of the research are that it is the first study looking at the individual bereavement experiences of Gypsies and Travellers, highlighting the impact that the high mortality rates and multigenerational premature deaths has on Gypsies and Travellers, particularly in relation to poor mental health outcomes. The study gives a voice to this vulnerable and marginalised ethnic group, highlighting the often frequent and traumatic bereavements they experience. The most significant outcome and strength of the research was the unexpected opportunity to include children within the study. This established that although very well cared for physically there is a lack of emotional support for bereaved .children. This finding led to the most tangible outcome of the research so far, the publication of the book *'it's different without you'* (Rogers, 2104), (see appendix 7), which provides the opportunity to discuss feelings following a loss. The book has been well received and positively reviewed by Traveller support organisations and individuals who have used it. It is also available to professionals through the CBUK bookstore. Dissemination of the research at both national and international conferences validates its importance as some of the research recommendations have already been met. Presentation of the research findings are now embedded into the Child Bereavement UKs' professional training programme and a factsheet has been produced for their website. The research has also been presented at conferences for the following organisations The Gypsy Lore Society, The Child Bereavement Network, The Traveller Movement and the Second world Congress on Resilience. The opportunities to share the research to these different audiences has strengthened the study by broadening the researcher's perspective and learning on key elements of the study, for

example, working with CBUK and the Child bereavement network increased the researcher's knowledge of children's understanding of loss and death and of how to provide support following bereavement, this was fundamental to the development of the children's book. In addition the presentation at the international congress on resilience led to a more detailed focus on stoicism and resilience and the identification of individual stoicism but collective community resilience. This focus also resulted in the publication of a journal article, (see appendix 8) and a forthcoming book chapter exploring the resilience of Gypsies and Travellers. These opportunities demonstrate the external interest in and value of the research.

Although there are many strengths to this research the limitations of the study also need recognition. The research is a small scale study carried out in the south of England and can only be considered representative of the research cohort. The research participants were women; no men were included in the participant sample because as stated in the rationale for the research, it is unlikely that Gypsy and Traveller men would engage in this type of research particularly with a female outsider researcher. As such the bereavement experiences and behaviours of men included in the study are viewed through the lens of the women participants rather than first-hand accounts from men. Thus the research is constructed only from a female perspective.

The unexpected opportunity to include children in the research broadened the range of participants, however similarly to the main study the children and young people that took part were all girls. As an opportunistic albeit deeply co-constructed, planned and regulated extension to the study the children's workshop was small with only seven participants. As such the feelings expressed during the workshop are representative of this small group and cannot be generalised without further and wider research. Similarly the findings suggest that early childhood bereavement experiences may have a long-term impact on adult mental health and wellbeing but further longitudinal research is necessary to confirm this.

Conclusion

The aims of this research were to gain an understanding of the cultural norms and community practices influencing the bereavement experiences of Gypsy and Traveller families. To identify whether the experience of bereavement has a long term impact on their life experiences and to establish if membership of a close-knit family and community with explicit cultural norms of bereavement and grief, offers effective support or potentially exacerbates the risk of long-term complicated grief.

The outcomes suggest that bereavement amongst this community does indeed have lifelong implications, as the cultural norms and community practices of English Gypsies and Irish Travellers appear to hinder grief responses. Current grief theory recognises that the bereaved learn to live with, or grow around their grief through the maintenance of continuing bonds with the deceased. The strong continuing bonds and heightened respect afforded to the deceased within Gypsy and Traveller communities mean that the dead remain interwoven in the lives of the living. Whilst this is perhaps a positive aspect facilitating grief responses, many other aspects of Gypsy and Traveller culture and lifestyles appear to have a detrimental effect on bereavement experiences and grief responses.

The challenges and complexities of Gypsy and Traveller culture discussed throughout this study means that they live with high levels of risk and vulnerability when compared to the mainstream population. Whilst, the strong family attachments that should provide the balance in their lives, and which in many ways help them to develop resilience to the hardships of life are important in supporting them through physical and practical struggles, resilience in the face of bereavement (something which is difficult for anyone to cope with) appears to be compromised by the overriding need to protect family members by asserting stoicism. In doing so may be compromised, risking ignoring the cost of individual emotional health and wellbeing with intergenerational impacts (Rogers, 2015). This is illustrated in participant B's story (see appendix one) which encompasses many of the culturally mediated

factors influencing the bereavement experiences of Gypsy and Traveller families, emphasising the complexities of individual loss and grief when interwoven with multifaceted cultural mores and familial relationships.

Moreover the findings suggest that cultural norms and practices associated with *'being a Gypsy/Traveller'* are a dominant factor influencing bereavement behaviours and experiences. For example stoic attitudes result in a fatalist acceptance of high mortality rates. This can be attributed to the separateness of lifestyles and poor education, particularly health education, resulting in an expectation of loss. This is particularly evident in the high suicide, maternal and infant mortality rates, where these often premature and potentially preventable deaths are common and accepted as the norm.

Likewise stoic attitudes also impact on children. High intergenerational mortality rates mean that children experience bereavement and are involved in death rituals from an early age. However, the overriding adult perception that children '*are too young to understand'* results in children's participation but without explanation and emotional support to aid their understanding of what they experience. The children involved in the research reiterated the importance of being able to talk about the deceased. Nonetheless the adult perception of what children understand and the cultural norm of not discussing death leaves a gap in the emotional support for bereaved children.

The often complicated grief responses and long term impacts of bereavement identified within this study can thus potentially be linked back to childhood experiences (although further research is needed to confirm this). The impacts of early childhood experiences on adult mental health and wellbeing are well evidenced and apparent in this study, as impacts of these are etched in the memories of the research participants influencing their adult experiences, individual resilience to loss and potentially perpetuating intergenerational grief responses.

The research also aimed to explore if community members feel that membership of a close-knit family and community, with explicit cultural norms of bereavement and grief offers effective support for managing the processes of loss, or potentially exacerbates the risk of long-term complicated grief. The findings suggest that grief is complicated by the nature of Gypsies and Travellers being *'very private people'* and the strong moral behavioural expectations .inherent in their communities These constrain the open expression of grief resulting in the long term complicated grief patterns found in this study. Although close kinship family and community provides effective physical support following bereavement emotional support is lacking as stoic attitudes and protective behaviours constrain the expression of emotion and discussion of grief.

The bereavement experiences and grief responses of Gypsies and Travellers are thus like many other aspect of their lives complex and exacerbated by their cultural heritage and lifestyle. Whilst there is recognition of the need for a specialist bereavement support service the challenge may well be in overcoming the stoic attitudes and engaging a community which holds explicit cultural norms of not discussing grief and loss in a bereavement support service based on talking therapy.

The opening quote of this thesis suggests that who we are shapes how we grieve; individually and socio-culturally. This is resoundingly true in the findings of this study where individual identity is interwoven within the cultural identity of being a Gypsy or Traveller, shaping individual grief responses.

Recommendations

The recommendations of this research are as follows:

- To raise awareness of the impacts of grief within Gypsy/Traveller communities through partnership with Gypsy/Traveller support organisations such as, the Traveller Movement, Friends Families and Travellers, Leedsgate, One Voice for Travellers.

The rationale for this recommendation is to increase the awareness of the health impacts of grief, particularly as Gypsies and Travellers experience frequent bereavements. The civil society organisations mentioned above have access to and are trusted by Gypsy and Traveller communities hence are well placed to disseminate information with some of the above agencies having considerable experience in delivering women's health promotion programmes.

- Working with Gypsy/Traveller support organisations and a range of practitioners around suicide prevention tools/interventions.

The literature review and research findings confirm the high levels of suicide within Gypsy and Traveller communities. Similarly to the recommendation above an awareness raising programme is needed to change the stoic and fatalistic acceptance of high suicide rates as a norm that exists within Gypsy and Traveller communities whilst simultaneously providing health information, tools and interventions to reduce the numbers of suicide and in particular bereavement related suicide.

Dissemination of this aspect of the study to the 'Help is at hand' suicide bereavement support programme, a partnership of bereavement support organisations, including Child Bereavement UK and supported by Public Health England and the Suicide Prevention

Alliance, would raise awareness of the high suicide rates within Gypsy and Traveller communities to a wide range of professionals.

- Develop specialist resources for piloting with Gypsy/Traveller children and families, for example the children's book, *its different without you*, produced as part of this study (see appendix 7).

The main research study identified the involvement of children in death rituals and whilst acknowledging that children are physically well cared for following bereavement there appears to be a lack of emotional support for bereaved children. In addition the outcomes of the children's workshop confirmed that protective behaviours prevent discussion of the deceased and associated feelings of grief. As a result children do not get the opportunity to remember and talk about the deceased, something they highlighted as a priority for them. The workshop supported the development and publication of a children's book as a resource to promote the discussion of loss, grief and the feelings associated with these but there is a clear scope for developing additional resources perhaps targeted at specific .groups of Gypsies, Traveller and Roma or different age ranges.

One hundred copies of the book were published with the project funding from Buckinghamshire New University's research challenge fund, these copies were sent to Gypsy and Traveller support organisations for distribution to bereaved Gypsy and Traveller families. The book is also available for sale through Blurb publications and via Child bereavement UK.

- Working with Child Bereavement UK and Gypsy/Traveller support organisations to train and support potential community counsellors and ensure that cultural awareness training is embedded into bereavement work.

The research outcomes identified the need for specialist bereavement support services but particularly highlighted the importance of external professionals and practitioners

understanding Gypsy and Traveller culture. Embedding cultural awareness training into programmes for bereavement counsellors and simultaneously encouraging Gypsy and Traveller community members to train in this field will help meet the identified need.

- Develop training resources for professionals to support cultural awareness training.

The aim of this recommendation is to work in close collaboration with Gypsy and Traveller NGOs and local community groups to provide training resources which support the development of cultural awareness training resources identified in the previous recommendation.

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Appendices

Appendix 1: B's Story

Note: Editing of the narrative to provide clarity for the reader is identified as follows: significant pauses are identified using bracketed numbers; for example, '(3)' would indicate a three-second pause whilst (…) indicates the omission and editing of some text and text within square brackets e.g. [information] are additions made by the researcher to provide clarity or context.

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This story illustrates the challenges faced by this family, exacerbated by the close family relationships and the mirrored life experiences of the two sisters, who married two brothers

and had simultaneous pregnancies, resulting in one stillbirth and one live birth. The complicated family relationships mean that their bereavement experiences are inseparably entwined.

Traveller family relationships are complex for a number of reasons. Family reputation is central to maintaining social capital within the community. Social capital relates to the support, goodwill and respect gained from membership of a group with shared values and beliefs and is perhaps more commonly recognised as strong community relationships, whereby group or community members support each other through social values, moral obligations and economically (Ryder & Greenfields, 2010). Gypsy and Traveller communities and economies are grounded in the principles of social capital hence the importance of keeping marriages within their own community, maintaining their cultural heritage. Moreover given that the Traveller community is relatively small most families are loosely related either through blood or marriage, so kinship marriage between cousins, or as in this case study sisters from one family marrying brothers from another is common practice (Liegeois, 2005; Clarke & Greenfields, 2006).

In addition a cultural hierarchy with distinct gender roles and responsibilities that govern social actions and behavioural practices are fundamental to community relationships, family reputation and respect. Highly respected family elders, who are often decision makers for the family, will influence relationships and familial roles and responsibilities (Cemlyn et al 2009). B discusses the impacts that this cultural and familial hierarchy has on her, meaning that she was unable to talk to and gain support from her mother or her husband following her miscarriages.

Although family relationships are discussed by B as being '*very, very close'* the closeness of family relationships refers to the physical closeness of living in close proximity however whilst physically close there is an emotional distance created by the strong protective behaviours that put other family members before individual needs. In this story the lack of

emotional closeness (and possibly emotional literacy) and protective behaviours resulted in avoidance being used as a coping strategy.

The bereavement focus of this case study is the loss of children, predominantly the stillbirth of B's nephew; this is further complicated by the live birth of B's daughter, the close physical likeness exacerbating the loss. In addition the unrecognised loss from three miscarriages intensifies her grief further.

Stillbirth and miscarriage are still commonplace within Gypsy Traveller communities as poor maternal health and infant mortality remain disproportionately high in comparison to the majority population (Lewis & Drife,2001; Parry et al, 2004; Matthews, 2008; AITHS, 2010; DH2010) (see further the literature review). Poor maternal health and the loss of her baby resulted in a long period of hospitalisation for B's sister.

This story highlights the challenges faced by hospitalisation, for this family, the lengthy stay in hospital was difficult as it separated family members, isolating the sisters from each other. Being in hospital creates a number of problems and anxieties for Gypsy and Traveller families. Firstly the close physical proximity within which families live, often seeing both close and extended family members on a daily basis means that hospitalisation separates family members perhaps for the first time in their lives. This close family relationship means that both immediate and extended family will hold vigils for the sick, these result in large numbers of family members visiting the hospital wanting to gather at the bedside. This often creates conflict with health service professionals as hospital facilities and procedures do not easily accommodate bedside vigils with large numbers of family members present.

Secondly the challenges faced by Gypsies and Travellers in accessing health care means that for the majority, and in particular those who live in sites or on the roadside, a lack of access to a local doctor increases the severity of illness by the time they reach hospital, thus hospitals are often feared and associated with death. Thirdly the lack of access and use of mainstream health services leaves Gypsies and Travellers unfamiliar with the hospital protocols. A lack of functional literacy, common amongst Gypsy and Traveller families,

compounds these difficulties resulting in a lack of health information and understanding of language and information shared by medical staff (Brack & Monaghan, 2007; Greenfields, 2008; Cemlyn et al 2009; Van-Cleemput 2010).

These problems are evident throughout the case study as B talks about a lack of information and understanding of what had happened to her sister's baby, creating fear for her own unborn child. Coupled with the miscarriages her fear for her unborn child is understandable. Whilst the lack of health information caused anxiety this was exacerbated by the fact that the loss of a child through stillbirth and miscarriage remains a cultural taboo. As B stated, she was unable to discuss her miscarriages with her husband or her mother. This is in part due to the cultural behavioural conventions surrounding gender and generationally appropriate topics of conversation, but also as a result of the protective behaviours that hinder close family communication relating to loss and grief. Moreover the stoic and altruistic attitudes exhibited by Gypsy and Traveller women, illustrated throughout B's story also create barriers to the expression of grief and to individual health and wellbeing.

The intensity of B's grief is defined by intensity of the mother/child attachment relationship. The loss of a child is recognised as one of the most significant and intense losses (Koopmans et al, 2013). For B there is some transference of her own hidden losses, the miscarriages, recognised through the stillbirth of her nephew, where she uses the physical space of her nephew's grave to mourn her own losses which are without social and physical recognition. B summarises the intensity of her loss of a child she never had with the poignant statement *'I never saw your face'*.

B's story illustrates the complexities of bereavement in Gypsy and Traveller families highlighting how the close family relationships are constrained by culturally mediated behaviours that create barriers to communication and familial support following bereavement. Moreover both cultural and religious beliefs and behaviours exacerbate grief responses.

Appendix 2: Vignettes used in focus groups

Marie has 3 children aged 5, 8 and 10 and a year ago lost a baby son as a result of a miscarriage. She had been prescribed pills to help her sleep initially but they ran out and the family had been moved on and were living in a trailer by the roadside. She had not been able to access a doctor or any more pills. Husband had been drinking more since the loss of the baby and she wasn't able to talk about it to anyone and no one seemed to recognise her loss. Everyone around her was sympathetic for the first few weeks but then it was as though nothing had happened and because there was no baby or funeral nobody remembered and Marie felt unable to grieve the loss of her child

Tommy has 3 children, the eldest Tommy having a family of his own. Tommy had experienced more than his share of bereavement having lost 2 sons and a grandchild. The 5 year old grandchild died in a roadside accident which his son never recovered from and committed suicide a few months later. The effect on the family was devastating especially as Tommy senior had already lost his younger son to suicide following problems with drugs and a prison sentence. The suicide followed when he was released from prison and realised the shame he had brought on his family.

Bridget's mother had a heart attack and Bridget was unable to grieve as she had suddenly become head of the family and was expected to be strong and support her family and found it difficult to find time for her own feelings. Bridget's children missed their grandmother and the youngest who was only 5 couldn't understand why her grandmother went to hospital and didn't come back.

Appendix 3: Scoping exercise questionnaire for agencies.

There is an increasing amount of research looking at the lifestyles and health of Gypsies and Travellers. Anecdotal evidence emerging from the research suggests a high prevalence of bereavement within this community and the underlying impact that bereavement may have on health and wellbeing. This research aims to identify what the bereavement support needs of children, young people and their families are following the bereavement of a close family member, and to establish if there is a need for a bereavement support service for Gypsy and Traveller communities.

The aim of this questionnaire is to establish what, if any bereavement support is available to and being accessed by Gypsy and Traveller communities

Please answer the following questions as fully as possible

Name of organisation.....

Has your organisation provided bereavement support for Gypsy and Traveller families?

Yes ☐ No ☐

If yes please briefly explain how and to whom support was given.
.....
..... Was support specifically for bereavement or did this arise from other services or support being provided

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

Do you think there a need for a specialist support service for the Gypsy and Traveller community?

Yes ☐ No ☐

Please comment on the reasons for your answer

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

Appendix 4: Summary of questionnaire responses from agencies

Questionnaires were sent to a number of organisations and professionals including Traveller support organisations, Traveller education departments, bereavement support organisations, NHS Trusts, hospices, health visitors and children's centres.

Organisation /professional	Questionnaire Responses		
Gypsy & Traveller support groups	Organisation provided support? Yes /No	How was support provided? to which G & T groups?	Is there a need for specialist bereavement support? Specialist support, peer trained support etc.
Irish Traveller Movement	Yes		Yes Peer trained support workers
One voice 4 Travellers	Yes		Yes Peer trained support workers & training for professional health workers, particularly in hospitals in understanding cultural awareness training to ensure awareness of traditions and beliefs surrounding death.
Friends, families and Travellers	Yes	Outreach, signposting to bereavement services and counselling, listening and general support through casework.	Yes Peer trained support workers

		Support provided for all Travellers; Romany Gypsies, Irish Travellers, New Travellers	
Derbyshire Gypsy Liaison Group	Yes		Yes
Leedsgate	Yes		Yes
Local authority Traveller education			
Buckinghamshire (Minority Ethnic & Traveller Achievement Service (METAS)	Yes	Role to deliver support to overcome educational barriers and have provided support for families dealing with bereavement and associated problems by, listening, signposting to support Cruse etc. information & guidance for schools, social care, housing and benefit support. Supported English (Romany) Gypsies, Irish Travellers and Fairground families (show people).	No There is a need for services to become aware of the needs of GRT communities so that support can be accessed when and where needed. This should be part of professional development training. Accessing the community is tricky – trust is essential element in work undertaken within the community and this takes time to establish. The communities themselves have strong extended family and this includes religious support On the whole we feel that the community rarely asks for any intensive specialist support re bereavement – it is more usually the support needed around coping with practical Doctors, Health Visitors and schools act as conduits for any further support which again clarifies the need for training on GRT cultural awareness rather than specific bespoke support.
Oxfordshire Community Liaison Teacher Equality and Diversity	No		Yes Services should be prepared to work with any community no matter how disenfranchised, through

Achievement Service (EDAS)			good practice, accessibility and trained in working with all areas of diversity, client need etc. It doesn't matter who as long as they understand and are trained in Traveller/ Gypsy culture.
Oxfordshire Traveller Education Unit.	No		Yes In my experience it is unusual for Travellers to access bereavement services outside the community. I have heard Irish Travellers say that it is not their way to talk to counsellors. However, I believe, in my past experience of working with a bereaved family as a teacher that there is a great need for support to bereaved families. Any service would need to be delivered at home through outreach. Bereavement counsellors would need to be introduced to the family through a familiar and trusted person, either professional or family member. Forms and professional language including writing notes should be kept to the minimum. As trust is built up the family themselves will refer family members to the bereavement counsellor and things can grow from there. Points to remember are that families often (not always) live in the moment so a service that can be quickly responsive to a phone call for support will have more success than one with a long referral lead in. Once the counsellor becomes known to the family they can/should attend funerals showing their respect and this will lead to greater trust. It is important that the counsellor is familiar with the culture and traditions around death; this will vary between Traveller groups so it is important to seek information from Traveller led organisations that can help to train potential counsellors.

Kent County Council Gypsy and Traveller unit	Yes	As part of wider support offered	Yes We at Kent County Council Gypsy and Traveller Unit, once made aware of the bereavement, offer our support to all members of the family and to the wider community. As a mark of respect we do not attend the site unless requested to do so by a resident. We liaise with police and other agencies to arrange traffic management for the funeral procession, if needed. We offer to contact bereavement services for those affected but this has to date always been refused.
London borough of Brent (Ethnic minority & Traveller achievement service)	Yes	Sent sympathy cards, visited families, attended funerals and provided financial assistance. Referrals made to bereavement services. Support provided for Irish Travellers.	Yes A specialist bereavement counsellor
Bereavement support organisations & Hospices			
Cruse Bereavement Care	Yes	One to one, face to face at the bereaved individual's home by experienced bereavement support volunteer - this person was known to and trusted by the Gypsy and Traveller communities. Support provided for Romany Gypsies, Irish Travellers and those identifying themselves as 'fairground Gypsies'.	Yes Peer support with back up support and guidance from local Cruse branch. The establishment of dialogue is essential to developing trust, which can be difficult with these communities.
Welomar Hospice Care Trust	No		Yes Anyone who has good professional structure with good awareness of diversity and difference

St Catherine's Hospice	Not aware of		No Support provided is set up to meet individual family needs regardless of background
Just 'B' bereavement support	No		No Services should be prepared to work with any community no matter how disenfranchised, through good practice, accessibility and trained in working with all areas of diversity, client need etc. It doesn't matter who as long as they understand and are trained in Traveller/Gypsy culture, death and dying theories and communication skills and be able to be OPEN to their needs and adapt bereavement support accordingly to this community's needs. The worker must also have training and experience in understanding development work/community and work hard at establishing trusting working relationships which may take time to form. The worker needs links into the communities or links with workers already linked 'cold calling' simply won't work.
Organisations supporting children			
Children's Society	Yes	Listening to people when they want to talk. Helping to identify information for bereaved families. Talking to coroner on behalf of a young person....Helping young people to express their feelings at anniversaries birthdays	Yes I think there would be a place for both. Trained peer support with specialist support worker as back up and for more difficult cases
Save the Children (Wales)	No		Yes Trained peer support
Ormiston Children's Trust	No		Yes Specialist support worker, already known and trusted by

			community
Children's Centres & family support workers			
Counsellor & Family support worker - Oxfordshire	Yes	. Informal support, listening (but not formal counselling) engagement with GP and counselling services, however counselling unsuccessful due to cultural barriers Support provided for Irish Travellers	Yes Specialist support workers and counselling services, most counselling services are not flexible enough to meet the needs of Travellers due to cultural barriers such as trust, finance, lack of support in keeping to timed appointments and lack of information or poor location.
NHS / Health visitors			
United Lincoln Hospital Trust, specialist family support, Palliative and bereavement care.	Yes	Family visits for bereavement following serious illness of child	No Support services should have training to work with Traveller communities but services should be equitable for all communities.
Health visitor, Hillingdon	No		Yes. Type of support dependent on individual need
Church / religious organisations			
Roman Catholic Diocese of Westminster	Yes	The support given is not on a formal basis. The Church, personified usually in the priest who would be performing the funeral, would be offering support during the process of arranging funerals with the Travellers. Travellers sometimes seek support from individual priests or Religious Sisters whom they know on an informal basis. On the whole, Travellers support each other on an extended family basis and are wary of seeking help from outside. Most of the support given is to Irish Travellers who have a strong allegiance to the Roman Catholic Church. Support is usually requested in the form of prayers and	Yes I think there is a need for this kind of support, but Travellers would be loath to seek it from an agency with which they are not already familiar. They are not very forthcoming in talking about feelings, particularly the men, and have little understanding of the psychology that goes with loss. I think trained peer group support would be the best option.

		Masses and sometimes in seeking reassurance about the person who has died. Bereavement support is not something that can be confined to the context of death; neither does it take place necessarily at the time of bereavement. It usually occurs within the context of a pastoral visit to a site or a family .for another unrelated reason. Support is often given immediately at the time that death has occurred, e.g. they might call for a priest to come or I might visit if I have heard of a death.	

Appendix 5 Participant information sheet

Participant Information sheet

Buckinghamshire New University and the Child Bereavement Charity are carrying out some research to find out about the bereavement experiences of Gypsies and Travellers to see if there is a need for a specialist bereavement support service for Gypsy and Traveller families.

We want to ask you about what might have helped you when you were bereaved.

Taking part in this research will help to see if there is a need for any specialist bereavement support services for Gypsy and Traveller families, and that any services developed understand and meet the needs of Gypsy and Traveller communities.

Taking part in the research will involve sharing your bereavement experiences, with the researcher. This will mean talking to the researcher in a small group with other bereaved Gypsies and Travellers and /or a one to one interview with the researcher where you will be asked to share your experiences and discuss how the bereavement affected your family and what may have helped your family following the bereavement.

Bereavement support will be available for you if you feel it would help you. This might be from one of the advisory groups, or a bereavement support service organisation in your locality.

The role of the Child Bereavement Charity during the project will be to provide support for the researcher and to help to find appropriate support services for participants if necessary. The Charity will not provide any direct support for participants to prevent a conflict of interest and biased research result

Anything you tell me will be confidential. Names, locations and where practicable personal details will be changed to make the stories as anonymous as possible whilst maintaining the authenticity of the stories and the research.

The interviews will be recorded so that I can remember everything you tell me accurately, the tapes will be destroyed at the end of the study.

All records will be kept in a locked filing cabinet

.

Guarantee

- We will only interview you if consent is given
- The interview will be recorded but will be confidential no one else will listen to it outside of the project and all names will be changed so that no one will be able to identify you
- If you decide you do not want to participate you can withdraw your consent at any time with no consequence to yourself.

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Participant information sheet for children's workshop

Children's book project - What about me, the good goodbye

Participant information sheet (for use with parents and children)

Buckinghamshire New University and the Child Bereavement Charity are carrying out some research to find out about how Gypsies and Travellers deal with grief when a family member or loved one dies. This is find out if there would be interest in Gypsy and Traveller families having special bereavement support. So far quite a few travelling people who have talked to us have talked about 'never getting over' grief and the pain going back to their own childhood. They've told us how hard it was for them to understand that death is the final goodbye and how deeply their parents grief felt. They have also said that Gypsies and Travellers look after their children so well but sometimes don't know what to tell children to help them understand. This project will work with Gypsy and Traveller children and young people using an expert story teller to help us find out children's feeling about loss and death. Using stories means that the children won't have to talk about their own loss or grief but they can talk about a story character's experience. That will help us to gain understanding about children's feelings of loss and death and what they think might have helped them to understand and come to terms. We would like children and young people to come to three workshops over several days in the summer holiday to listen to stories and take part in the project.

We want to record the story-telling workshop so that we can listen to the children's own words again. We will ask children to take photographs or help Mary Humphrey to take photos which explain how they feel about death, and the children may also make drawings to explain feelings and understanding. After the workshops the words, drawings and pictures will be used to make a book for parents to use to help children understand loss and death as well as Gypsy and Traveller customs and ways of respecting the dead.

Thank you for thinking about taking part in this project.

Guarantee

- We will only interview you/your child if consent is given
- The workshops will be recorded and photographed but we will only use you/your child's words and pictures with your permission. We will not use you/your child's name unless you give permission.
- If you decide you/your child do not want to participate you can change your mind and stop at any time.

Content removed on data protection grounds.

Appendix 6 participant Consent form

Consent form
Please tick each box

I ..... agree to be interviewed for the research study investigating the bereavement experiences of Gypsies and Travellers. ☐

I have read / been told about the participant information sheet and I am willing to be interviewed. ☐

I understand that I can stop the interview or withdraw from the project at any time without giving an explanation ☐

I have read / or had read to me and understood the information sheet ☐

I have had the chance to ask questions about it. ☐

I am free to change my mind and withdraw from the study at any time. ☐

I agree to the research interviews being audio taped. ☐

I understand that the information collected will be confidential and stored in a locked cabinet accessed only by the researcher ☐

I am willing to participate in the study ☐

Participant name .....

Participant signature / mark ..... Date .....

Witness name / signature if participant makes a mark .....

Researchers name .....
.
Researchers signature ..... Date .....

Participant consent form for the children's workshop

Please tick each box

I ..... give consent for my child /children to take part in the story workshops. ☐

I have read/been told about the participant information sheet and I give consent for my child/ children to take part ☐

I have read/or had read to me and understood the information sheet ☐

I understand that I can withdraw my child/children from the project at any time without giving an explanation ☐

I have had the chance to ask questions about it. ☐

I agree to the story workshops being audio taped. ☐

I understand that the information collected from the story workshops and photographs taken will be used in the production of the book / DVD ☐

I consent to my child/children taking part in the project if they wish to ☐

Parent s name ..... Parents signature/mark ..... Date .....

Witness name/signature if parent makes a mark .....

Researchers name .....Researchers signature ..... Date .....

Young person's consent ..... Date .....

Childs consent

I am happy to take part in the story workshops and photographic sessions, but can stop at any time I want t to.

Yes ☐ No ☐

Name .....

Appendix: 7 Children's book: It's Different without you.

The book project ...

This book has been developed as part of a research project looking at the impact of bereavement in Gypsy and Traveller families. An outcome of the project identified that following a family bereavement children are very well cared for physically, but that often they need some emotional support to be able to talk about the person that has died and how they feel.

The overriding message from the children and young people taking part in the project was the importance of memories and being able to talk about and remember the person who has died.

Notes for parents and carers using this book

This book is designed to be used with children who need help to understand what death means, what we do and how we feel when someone dies.

Talking about someone who has died can be hard for Gypsies and Travellers, but it is important for children to be able to ask questions and understand what is happening.

Children may ask questions and it is best to listen to exactly what the child is asking and answer as honestly as you can giving them the information they need. If the child wants to know more they will ask other questions when they are ready.

If the person who has died was also very special to you, this may seem hard at first, but as you share your stories and memories with the child you will find that you can laugh and cry together whilst remembering the person who has died.

it's different without you

When someone you love dies some things will be different...

The person who has died will not be around anymore.

There will be a funeral, this is where you can say goodbye to the person who died, remember them and celebrate their life. This might make you feel sad and happy at the same time , remembering things that you did together .

Somewhere to remember...

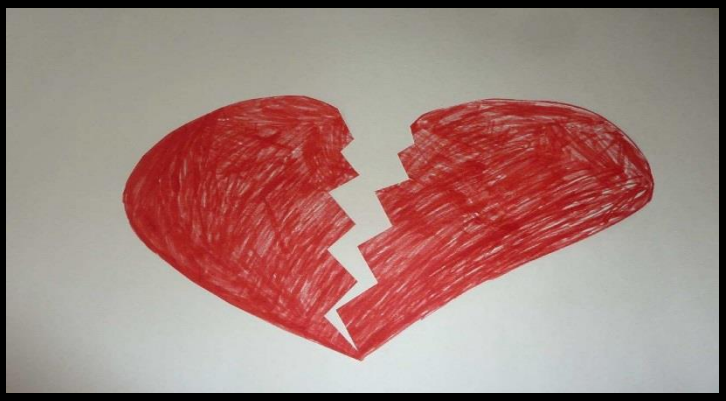
When someone dies they don't need their body anymore so it is put in a special garden, called a grave. This is somewhere where you can go to visit on birthdays and anniversaries or anytime you want to.

Things will be different when someone dies ...

What is different for you ?

it's different without you

When someone you love dies
you might feel funny inside, as if your heart is broken.



You might have lots of feelings all at once ...

it's different without you

Like some of these...

Sometimes you will feel sad ...

Its OK to feel sad ...

You might feel angry , and that's ok too ...

it's different without you

And sometimes you might feel ...

Happy...

It is Ok to be happy and have fun, but that does not mean that you do not love and miss the person that has died.

When someone you love dies you will have lots of different feelings ...

How do you feel?

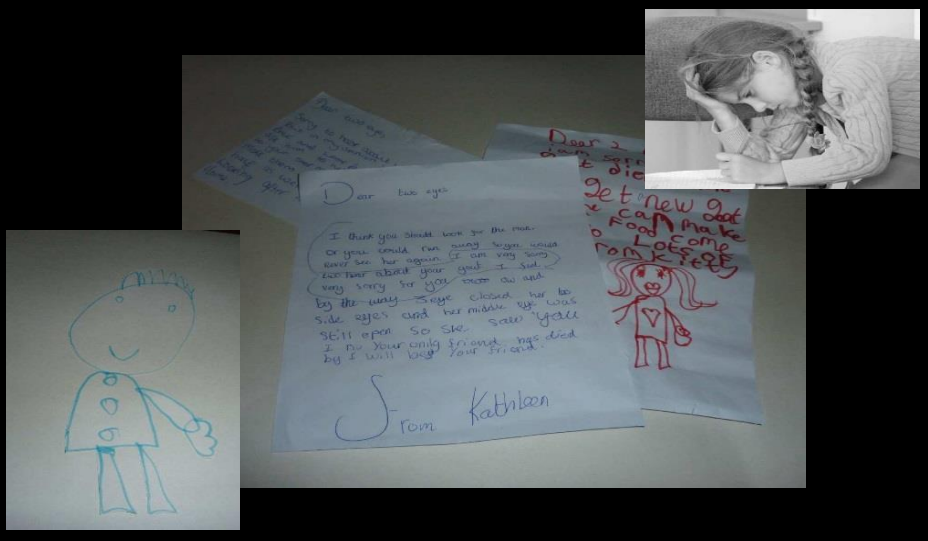
Remembering the person you love can help, sometimes memories will be sad but remember the happy times too ...

it's different without you

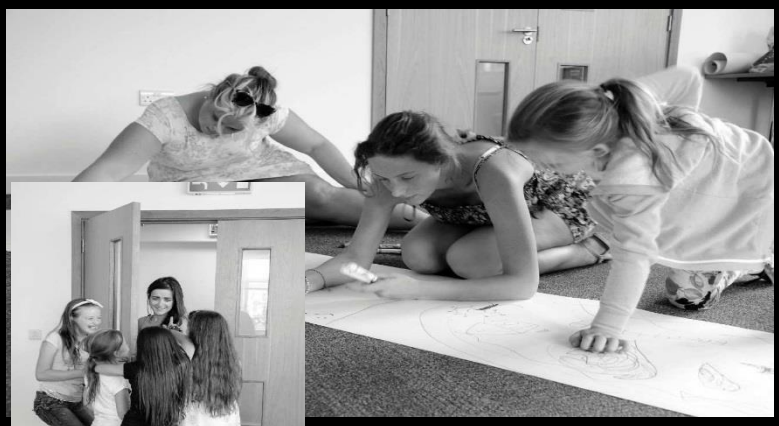
What do you remember...

What do you think might help you feel better?

Drawing or writing things down might help

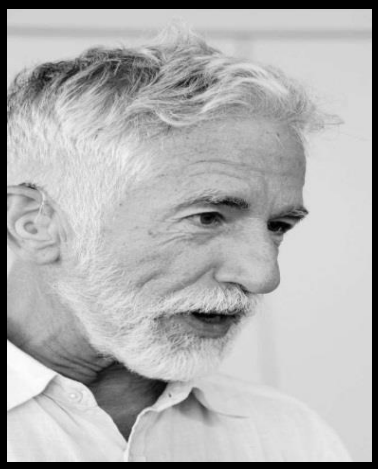


Talking to friends can help too …



it's different without you

Or for someone to listen to you …



It's different without you

You might have lots of questions you want to ask...

Do you have any questions ?

Remember...
when someone you love dies you
will have lots of different feelings,

Remember ....

Some things will change, but the memories that you have will always keep the person you love close to you.

Remember you are not on your own,
Find someone to talk to , if your mum and dad are too sad to talk about it maybe you friends, your granny, or your teacher can help.

Need more help?
Child bereavement UK are a national bereavement support service for children and families.

www.childbereavmentuk.org 01494 568900

Appendix 8: Journal article

Submitted to: Today's Children Tomorrow's Parents No. 40-41 June 2015

Beyond bereavement: exploring resilience in Gypsy and Traveller families following bereavement.

Abstract:

There are an estimated 3000,000 Gypsies and Irish Travellers in Britain. Despite Romany Gypsies, Irish Travellers and Scottish Gypsy-Travellers being recognised as distinct ethnic groups, in recent decades these communities have faced increasing challenges to retaining their culture and traditional nomadic lifestyle with significant impacts on their health and wellbeing. In addition to facing inequality and discrimination Gypsies and Travellers experience significant health inequalities and have a life expectancy which is considerably less than surrounding populations.

Bereavement is a significant health concern for Gypsies and Travellers with considerably higher levels of suicide, maternal and infant mortality, miscarriage and stillbirth than in wider society. Multiple bereavements can result in long term health implications including depression, anxiety, and increased risk taking behaviours, including alcohol and substance misuse and complicated grief reactions in adults. In addition the close knit nature of Gypsy and Traveller communities means that the death of a relative is felt with great intensity articulated by some research participants as an event with which they "never come to terms". The significance of bereavement and loss within these groups can therefore result in a continuum of loss and complicated grief throughout the lifespan.

However, the effects on children of significant loss, or living with carers who are experiencing bereavement remain largely unrecognised, despite the increasing research evidence which explores the connection between early childhood experiences and later life chances.

This paper presents emerging findings from my on-going PhD studies exploring the bereavement experiences of Gypsies and Traveller families, and considers resilience in relation to the bereavement experiences of this marginalised ethnic group.

Key words: Gypsy, Traveller, Bereavement, Resilience.

Introduction

'What doesn't kill you makes you stronger' (Irish Traveller woman in her late fifties Roger's unpublished data).

The statement above made by a participant in my on-going bereavement research reflects the stoic nature and resilient attitude found within Gypsy and Traveller families and communities experiencing hardship. Moreover, it summaries acceptance of life-long challenges and adversity faced by Gypsy and Travellers living a marginalised lifestyle within mainstream society.

Living on the edge of mainstream society British Gypsies and Travellers (the standard terminology used in the UK to refer to members of the ethnic group included in European policy documents as 'Roma' communities, see further: Council of Europe (2012) [1] remain largely hidden or invisible. Whilst there is limited space in this paper to detail all the risk factors faced by these communities, they are vulnerable across all aspects of the life-course, including experiencing high rates of premature death. Hence bereavement and complicated and long-term unresolved grief underpins high levels of mental illness (depression and anxiety) in Gypsy and Traveller communities.[2,3] However despite the challenges faced Gypsies and Travellers, community members, and particularly women have been found to have a very stoic attitude towards life [4,5] as illustrated in the opening quotation. However this paper sets out to question whether when faced with repeat bereavement, communities are behaving stoically or exhibiting psychological and social resilience?

Resilience relates to an individual's capacity to recover from adverse life experiences including trauma and high levels of stress [6].The complex lifestyles led Gypsies and Travellers (i.e. often experiencing poverty and homelessness or insecure accommodation) typically involves experiencing high levels of trauma and stress, both on an individual level and also collectively as members of a marginalised ethnic group. Thus Gypsies and Travellers have been identified as being vulnerable to both individual and 'cultural trauma' through their communal experience of membership of a group whose traditional ways of life is increasingly criminalised and stigmatised in sedentary post-modern society. Individual vulnerability is therefore exacerbated by collective cultural trauma which impacts on social dynamics, emotions, spirituality and the resilience of those involved and additionally, can have intergenerational impacts on coping mechanisms leading to increased emotional vulnerability. [7]

This paper explores research participants' capacity for resilience by considering the risks and protective factors faced by Gypsy and Traveller families. In order to set the scene it is important to clarify who are Included within this definition

Who are Gypsies and Travellers?

In Britain, 'Gypsies and Travellers' is a generic term used to identify members of ethnic groups who are traditionally nomadic. Defining who is a Gypsy and Traveller is however relatively complex, with different formulations found in planning law, which is based on nomadism (as still practised by a considerable number of Gypsy/Travellers in the UK) and under the Race Relations Acts which provides protection for individuals who are members of ethnic groups. It is important to recognise that there are a number of distinct groups commonly included within the generic term Gypsies/Travellers, e.g. English Romany Gypsies, Welsh Gypsies, Scottish and Irish Travellers, Show People, (Fairground Travellers) Bargees (barge or boat dwellers) European Roma and New Travellers [8]. For the purpose

of this paper the term ‘Gypsies and Travellers’ is used to refer simply to English Romany Gypsies and Irish Travellers the largest of these populations in Britain.

Despite estimates that there are approximately 300,000 Gypsies and Travellers in the UK, [9] they remain a largely hidden community in mainstream consciousness. In part this invisibility is used as a protective strategy by the communities, to maintain their distinct cultures and heritage and also to prevent assimilation into the sedentary society. [10]. However, invisibility also keeps them marginalised and misunderstood by the wider population, creating a dichotomy of views, from the historic and romanticised notion of glamorous beauties leading a nomadic lifestyle with horse drawn wagons in country lanes, juxtaposed against the more recent stereotypical view of ‘dirty’ and ‘dishonest’ people living in illegally parked caravans. [5,11] The reality is in fact more complex as may be expected of a marginalised community who have experienced a long history of prejudice and discrimination dating back to the Sixteenth century when they were first identified as present in the UK.

The separateness and lifestyle choices favoured by many Gypsies and Travellers, which is often at odds with mainstream sedentary society, has resulted in a complex and difficult relationship between Gypsies, Travellers and the state. [9, 10, 12]. Consequently increasingly repressive laws and social and economic exclusion has led to Gypsies and Travellers having the poorest life chances of any ethnic group in the UK [14,15], Furthermore the marginal physical places occupied by many Gypsies and Travellers often adds to the high levels of exclusion they experience, increasing their vulnerability across all aspects of life, in particular in relation to accommodation, heath, education and employment risk [16]. This is particularly evident when considering the poor health status and rates of premature mortality found within Gypsies and Traveller communities when they are compared to mainstream populations, including individuals with low socio-economic status. [2]When this multi-factorial exclusion is added to a high rate of multi-generational premature bereavement from

accidents or preventable deaths etc. it means that the individual and socio-cultural significance of death remains at the forefront of Gypsies and Travellers experience.

The impact of bereavement on Gypsy & Traveller communities

Although death and grief are universal, the place of the dead in society, mourning rituals and the manifestations of grief vary greatly across cultures.[7,17] Thus culture, societal traditions and beliefs create understandings about death, and provide a framework for bereavement behaviours through determining the influence that the dead have on the lives of the living. [18, 19, 20]

Whilst death remains central to shaping the behaviours of Gypsies and Travellers, often played out through strong cultural traditions and religious beliefs; within the community there also appear to be explicitly contradictory models of bereavement behaviours, with overt expressions of loss, lavish funerals and complex death rituals, whilst the experience of 'grief' (defined as the emotional response to bereavement and loss that has both physical and psychological consequences that may impact on health[21,18] itself stays firmly hidden and is often unresolved for many years. [5.,3] In order to understand the phenomenon of long-term complicated grief it is necessary to understand the close knit nature of the Gypsy and Traveller families who are typically defined through a collective culture with each person's well-being and identity connected to membership of their family and kinship group rather than primarily operating as an autonomous individual.

The close-knit nature of Gypsy and Traveller life (which in many ways remains unchanged from the models found in pre-industrial rural societies) means that following a death, public displays of grief, and open recognition of the enormity of loss both to private individuals and the community at large, are central to both demonstrating the value of that person and acknowledging the ways in which life is changed forever by the loss of a community member. Failure to respect these social norms is almost unthinkable for the vast majority of Gypsies and Travellers, with individuals often travelling for many hundreds of miles to 'show

respect' and support a recently bereaved family. Not uncommonly a funeral – regardless of the age of the deceased person, or the circumstances of their death – might attract several hundred mourners. Moreover should a breach of 'respect' such as sending flowers or attendance at the funeral or at the 'sitting up' with the family the night before occur, (even if social breaches may have existed in the past between families), individuals would behave in such a way report that they would feel both personally diminished and risk of being socially ostracised.

So why does this central focus on death and appropriate behaviours remain so crucial to Gypsy and Traveller identities? Firstly, the relatively unchanging family structures and 'traditional' values common to the overwhelming majority of Gypsies and Travellers means that there is an exceptionally high level of contact between kin groups on a daily basis. This is in complete contrast to the majority of 'Western' communities where families tend to be smaller, more disparate and geographically dispersed. Thus, an individual might spend their entire life living alongside their parents and siblings, on a caravan site, with their own children growing up, marrying and having their own family whilst living either at the same location or geographically nearby. Hence almost by definition, living in an extended family unit, the repercussions of birth and death are likely to have a greater impact and deeper resonance than for individuals who are unable to live in such close proximity to their wider family. The close kin-ship structure of Gypsy and Traveller communities means that the death of a relative is felt with great intensity, articulated by some research participants as an event with which they "never come to terms". The significance of bereavement and loss within these groups can therefore for some people result in a continuum of loss and grief throughout the lifespan, particularly (as touched upon below) there are cultural factors which preclude seeking external psychological help with unresolved grief, leaving sufferers with no option but to 'cope' stoically, or resort to 'self-medication' such as alcohol or drugs to numb the pain of loss.

Resilience factors within Gypsy and Traveller communities.

Having outlined the factors which lead to increased grief reactions, amongst Gypsies and Travellers it is time to consider the strong protective factors which aid resilience and survival for individuals experiencing repeated trauma. Many of these resilience factors, like those which exacerbate risk of unresolved grief, are embedded within their close family networks. Rutter 1981[22] identifies a number of domains (both personal and environmental) by which individual capacities for resilience can be measured against the dominance of risk and protective factors within each person's life. Personal domains include personality traits and gender, capacity to cope with stress factors and change and family influences, whilst environmental factors include living conditions. It is impossible to separate personal and environmental factors where Gypsies and Travellers are concerned, as their nomadic traditions are increasingly compromised and an insecure living environment may be a significant cause of stress, with fear of eviction, prejudice and persecution common concerns amongst research participants. In addition, poor and dangerous living environments account for a number of intergenerational sudden unexpected deaths such as those associated with traffic accidents or poor environmental health. Negative family circumstance can also result from accommodation change with families being 'broken up' and unable to live in the close proximity that they are used to. In addition, bereavement will also have a significant effect on family with changing roles and responsibilities. [3] Thus, whilst the closeness of family is a strong protective factor associated with resilience, changes in circumstances such as those outlined above can also create additional stress factors. Rutter's (1981) consideration of personality traits and gender roles is particularly pertinent to Gypsy and Traveller families as he highlights psycho –social stressors in male patients, particularly those linked to family discord, proposing that males are more vulnerable and less resilient than females to stress. Evidence of male responses to family bereavement stressors within Gypsy and Traveller families in my research (and earlier literature), repeatedly note high incidences of risk taking behaviours and bereavement-related suicide; supporting Rutter's proposition of increased

male vulnerability. In contrast Gypsy and Traveller women are often responsible for keeping the family together and demonstrate a stoic or resilient attitude of ' just getting on with it' (Irish Traveller woman aged 45, Roger's unpublished data)

Overall, whilst positively correlated resilience markers are clearly found within Gypsy and Traveller culture and traditional family structures: predominantly secure emotional attachments, strong relationships; the availability of emotional support; security, and a structured family environment with clear and consistent boundaries. [22,6] all of which were noted by respondents as fundamental to Gypsy and Traveller values; the overriding cultural need articulated by interviewees to "protect family at all cost" may, as normatively practised, be detrimental to developing personal support and resilience. Thus, my current research findings strongly suggest that the desire of Gypsy and Traveller respondents to protect family members through not talking about the deceased person, ignoring others' pain and simply 'getting on with it' may be detrimental to individual emotional resilience; as grief is internalised. Hence the desire to alleviate grief, and culturally accepted way of protecting family members from pain by avoiding the subject of death and loss is so strong that it seems to create personal vulnerability rather than increased emotional protection for some vulnerable individuals.

This protective attitude is summarised by this interview extract,

'If it's a member of your own family, your brother or sister, you can't show your feelings you can't because you are afraid to hurt them, you have to keep a brave face on it' (Irish Traveller woman, Roger's unpublished data).

Conclusion

The role that family and community play in supporting health and wellbeing is highlighted in Marmot's (2010)[23] discussion of social capital, where he suggests that close relationships between individuals promote resilience and provide barriers to exacerbated health risk. In

contrast, I suggest however that a lack of inter-generational resilience and learnt responses to grief and bereavement as enacted in the current case, is likely to result in the high levels of grief related mental health problems experienced by Gypsies and Travellers.

In conclusion the challenges and complexities of Gypsy and Traveller culture outlined above, means that they live with high levels of risk and vulnerability when compared to majority cultures. Whilst, the strong family attachments that should provide the balance in their lives, and which in many ways help them to develop resilience to the hardships of life are important in supporting them through physical and practical struggles, resilience in the face of bereavement (something which is difficult for anyone to cope with) appears to be compromised by the overriding need to protect Gypsy and Traveller family members by asserting stoicism, and in doing so, risking ignoring the cost of individual emotional health and wellbeing with intergenerational impacts.

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