

This is an accepted manuscript of an article published by Taylor & Francis in the Journal of Bereavement Care on 8 December 2017, available online:

http://www.tandfonline.com/10.1080/02682621.2017.1390281

Hidden Losses and 'Forgotten' Suffering: The Bereavement Experiences of British Romany Gypsies and Travellers

Authors: **Carol Rogers**<sup>1</sup>, (Senior Lecturer, Department of Community Care, Education and social sciences 522141x4211 **and Margaret Greenfields**<sup>2</sup> (Professor of Social Policy and Community Engagement/Director of IDRICS) Margaret.Greenfields@bucks.ac.uk 01494 522141x5770

**Abstract:** There are an estimated 300,000 Romany Gypsies and Travellers resident in Britain. Policy enactments and a decline in stopping places have impacted these ethnic minorities' 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 10–12 years compared to 'mainstream' populations. Further, considerably higher levels of suicide, maternal and infant mortality, miscarriage and stillbirth are reported. Membership of close-knit and large extended families means that bereavement experiences are common from an early age. Unresolved grief from multiple bereavements can have long-term health implications, including depression, anxiety, and increases in risk-taking behaviours, including alcohol and substance misuse.

This paper presents findings from a recently completed study that examines the bereavement support needs of Gypsies and Travellers and best practice for organisations seeking to support these 'hard to reach' populations.

ABSTRACT: 149 words.

Keywords: Gypsies/Travellers; Bereavement; Suicide; Health Exclusion; Grief

MS length (excluding references/acknowledgements etc): 5757

References: 900

-

<sup>&</sup>lt;sup>1</sup> Corresponding Author: Carol Rogers Carol.Rogers@bucks.ac.uk

<sup>&</sup>lt;sup>2</sup> Both Authors can be contacted at the following Postal Address: Institute for Diversity Research, Inclusivity, Communities and Society (IDRICS), c/o Room E3.03; Buckinghamshire New University, High Wycombe Campus, Queen Alexandra Road, High Wycombe, HP11 2JZ

#### Introduction

This paper discusses the limited research and data on premature death and grief behaviours amongst British Romany Gypsy and Traveller populations<sup>i</sup>, and presents findings from the first author's doctoral research into the experiences of bereavement, complicated grief, and best practice in developing culturally appropriate support for members of the above communities. Gypsies and Travellers are under-represented in the use of bereavement support services whilst experiencing a disproportionate rate of (often premature or unexpected/violent) death compared to 'mainstream' populations. This study builds upon research undertaken by the second author into Romany Gypsy and Irish Traveller communities' experiences of health service engagement, which identified findings pertinent to bereavement experiences and complicated grief reactions amongst the above populations (Rogers, 2016, Greenfields, 2008, Clark & Greenfields, 2006)

## Defining the populations considered within this study

The phrase 'Gypsies and Travellers' (see endnote 1), is a generic term used in the UK to identify members of ethnic groups who were (or are) traditionally nomadic. Defining who precisely is a Gypsy or Traveller is however, relatively complex, with different formulations found in planning law (based on nomadism regardless of ethnic origins) and under the Race Relations Acts. Despite being recognised as minority ethnic communities under the Race Relations and Equalities Acts (see Cemlyn et. al., 2009; Clark and Greenfields, 2006), Gypsies and Travellers have been described as being "some of the most vulnerable and marginalised ethnic groups" in British society, as reflected by poor access to education, bad health and unequal access to services (Commission for Racial Equality, 2006; EHRC, 2016). This unenviable social status pertains to this day as evidenced by persistent localised research reports, Government reviews and European monitoring reports (ERTF, 2014; EHRC, 2016)

## The research study

The doctoral study explored the impact of bereavement on individuals and wider family members with consideration given to the close cognate kinship and collectivist nature of Gypsy and Traveller communities. It considered whether and how bereaved individuals are supported in a family and community context, given that death and loss

are not typically openly discussed within this ethnic group (Clark and Greenfields, 2006).

Female participants (see Table 1 below) were recruited via non-government organisations (NGOs) that provide advocacy and support to Gypsy/Traveller communities by promoting social inclusion and equality with mainstream society. The sampling choice to only include women was deliberate, following recommendations from the advisory NGO groups, and predicated on the highly traditional gender role behaviours of Gypsy and Traveller men. It was felt highly unlikely that males would talk about bereavement, (a subject that they do not typically discuss even within their own community) to a non-Gypsy female researcher (Okely, 1983). This focus on gendered experience has situated the research as closely aligned to feminist paradigms (Ropers-Huilman & O'Brien, 2015). Given the sensitive nature of the research, narrative inquiry using focus groups and narrative conversations were utilised to explore the bereavement experiences of the participants (Gilbert, 2002). Two focus groups, one with eight Irish Travellers and the other with seven English Romany Gypsies were carried out, followed by a further nine individual narrative conversations.

## **Analysis**

A thematic analysis of the data identified the following themes: cultural characteristics, health status, gender and family all of which were influential in shaping the bereavement practices and behaviours of Gypsy and Traveller families. The stories heard during this study confirm that bereavement typically 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. Embedded in these kin 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 appear to have an impact on complexity of bereavement behaviours of Gypsies and Travellers. It is particularly notable amongst women who will consistently put the care and protection of other family members above their own health and wellbeing, as illustrated in the interview extract 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. 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 how 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' (Irish Traveller interviewee).

Table 1 presents the demographics of the research participants and their bereavement experiences, emphasising the high numbers of premature and potentially preventable deaths experienced by respondents and their families.

Table one: Demographics of Research Participants and their bereavement experiences.

| Participant profile                 | Relationship of deceased to participant        | Age at death                                | Mode of death   |
|-------------------------------------|--|---|---|
| Irish Traveller<br>Living on a site | Mother   | 59  | Cancer  |
| Irish Traveller<br>Living on a site | Nephew<br>Children<br>Cousin                   | Pre -natal<br>Pre -natal<br>9               | Stillbirth 3 Miscarriages Undisclosed   |
| Irish Traveller – housed            | Son  | Late thirties                               | Substance misuse  |
| Irish Traveller                     | Brother in law                                 | 16  | Road traffic accident   |
| Living on a site                    | Brother in law Cousin                          | 21 7  | Road traffic accident Road traffic accident   |
| English Gypsy –housed               | Uncle<br>Grandfather                           | 30<br>Undisclosed                           | Sudden, cause unknown Sudden, cause unknown   |
|                                     |  |   |   |
| Irish Traveller<br>Living on a site | Children  Mother                               | 2 weeks Pre- natal undisclosed              | Meningitis 5 miscarriages and stillbirths Head injury                               |
| English Gypsy -housed               | Child  | Pre- natal                                  | Stillbirth  |
| English Gypsy –housed               | Child<br>Grandson<br>Brother<br>Sister in law  | 15 months<br>23<br>33<br>38                 | Gastro enteritis Sudden (possible suicide) Cancer Blood poisoning                   |
| Irish Traveller<br>Living on a site | Brother Cousin Cousin Cousin Cousin Aunt Niece | 39<br>28<br>54<br>24<br>41<br>37<br>3 weeks | Suicide Suicide Cancer Pneumonia Suicide Cancer Sudden infant death syndrome (SIDS) |
| Focus group 1                       |  |   |   |
| Irish Traveller<br>Living on a site | Grandchild                                     | Pre-natal                                   | Stillbirth  |
| Irish Traveller<br>Living on a site | Mother   | Undisclosed                                 | Respiratory disease (anticipated death)   |
| Irish Traveller<br>Living on a site | Grandmother                                    | Undisclosed                                 | Undisclosed   |
| Irish Traveller<br>Living on a site | Children                                       | Pre-natal                                   | 2 miscarriages  |
| English Gypsy –housed               | Grandfather                                    | Undisclosed                                 | Sudden , cause unknown  |
| Irish Traveller                     | Children                                       | Undisclosed                                 | Sudden infant death syndrome  |

| Living on a site             |               |             |                       |
|------------------------------|---------------|-------------|-----------------------|
| Irish Traveller              | Mother        | Undisclosed | Unknown               |
| Living on a site             |               |             |                       |
| Irish Traveller              | Children      | Pre-natal   | 3 miscarriages        |
| Living on a site             |               |             |                       |
| Focus group 2                |               |             |                       |
| 7 participants not all       |               |             |                       |
| identified specific personal |               |             |                       |
| losses.                      |               |             |                       |
| English Gypsy                | Mother        | Undisclosed | Undisclosed           |
| Living on a site             |               |             |                       |
| English Gypsy                | Mother        | Undisclosed | Undisclosed           |
| Living on a site             | Father        | Undisclosed | Heart attack          |
| English Gypsy                | Sister in law | 30          | Road traffic accident |
| Living on a site             |               |             |                       |

The striking feature of the data within this table is the mode of, and age at which, deaths occurred, many of which are potentially preventable losses when compared to mortality patterns within 'mainstream' populations. For example, within mainstream society the death of a fifteen month old from gastro-enteritis is unlikely to occur today, as although a common childhood illness in the UK only seven per thousand cases require hospitalisation whereas current mortality rates for this condition are mainly attributed to developing countries and minority populations such as Australian Aboriginals (Elliot, 2007), further reinforcing the disparity in health between majority and minority populations internationally. The table confirms anecdotal evidence that many of the bereavements experienced by Gypsies and Travellers are sudden, unexpected and often traumatic, with high numbers of road traffic accidents, suicide and infant and childhood deaths.

# Contextualising Gypsy and Traveller Experiences of Death in the 21st Century

Today, in post-modern Western society, whilst membership of religious denominations and culturally familiar rituals may still play an immediate role in supporting families in the aftermath of a death (Parkes and Prigerson, 2010), the widespread decline in religious belief and observances (Crabtree, 2015), coupled with societal changes which have seen the removal of 'traditional' mourning from public life, have led to expectations that grief should be expressed privately rather than openly. However, there are certain exceptions, such as the relatively recent growth of wayside shrines marking roadside accidents or violent deaths (Hockey et al, 2001).

However, in stark contrast to the way in which death is presented and discussed in mainstream Western society, rituals of death and public and community-affirmed mourning remain central to Gypsy and Traveller community practice for a number of reasons.

The close-knit nature of Gypsy and Traveller life (Greenfields, 2006) means that public displays of grief, and open recognition of the enormity of loss, are central to demonstrating the value of a 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 in the UK and in the wider European Roma context (Williams, 2003), with individuals often travelling for hundreds of miles to 'show respect' and support a recently bereaved family. Regardless of the age of the deceased person, or the circumstances of their death, funerals 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 (Clark & Greenfields, 2006), occur (even if social breaches may have existed in the past between families), individuals would behave in such a way that they would feel both personally diminished and risk social ostracisation. The depth of mourning and duration of grief reactions expressed by respondents within our research is so profound, (and indeed widely accepted as a commonplace response to bereavement), that it can potentially be argued that Gypsy and Traveller cultures normalise, what in other contexts could be seen to be as 'complicated' or 'pathological', grief (Shear et. al., 2011).

So why does this central focus on death and 'appropriate' behaviours remain so crucial to Gypsy and Traveller identities and behaviour? What are the implications for family functioning and recovery from grief, when there is such a focus on remembering the dead and mourning so profoundly over long periods of time?

In order to understand the cultural and practical implications of bereavement experienced by members of these communities, it is important to recognise that 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 occurs particularly amongst families' resident on 'sites', although it is also commonly found amongst housed members of the communities who prefer residing in 'enclaves' with close kin (Smith and Greenfields, 2013).

These patterns of close co-residence are in complete contrast to the majority of 'Western' communities, where families tend to be smaller, more disparate and geographically dispersed. Thus, a Gypsy or Traveller might spend their entire life living alongside their parents and siblings, on a caravan site, reaching adulthood, marrying and having their own family, whilst living either at the same location or geographically close to their birth family and often those of their spouse. Thus, almost by definition, for those 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.

Furthermore, unlike the majority of mainstream populations who are increasingly employed in non-manual settings, working with unrelated individuals, Gypsies and Travellers frequently work in extended family groups, and engage in manual labour such as market trading, tarmacking, and scrap metal dealing (Ryder & Greenfields, 2010). These forms of labour, coupled with poor access to medical care (Matthews, 2008) are often associated with premature morbidity and mortality, to the extent that Diacon et. al. (2007:1) asserts that 'Gypsies and Travellers have the poorest life chances of any ethnic group in the UK'. Consequently, mortality rates within Gypsy and Traveller communities are significantly greater than that of the general population.

Moreover, as discussed by a number of authors (Parry, et. al., 2004; Matthews, 2008; Cemlyn et. al, 2009), there is a significant over-representation of early deaths resulting from undiagnosed cancers, poorly controlled diabetes and cardio-vascular disease. There is also a high rate of traumatic deaths amongst these communities, often occurring as a result of suicide, road traffic accidents and preventable maternal and infant mortality (Cemlyn et. al., 2009). Clearly in the case of these populations, prematurity of death compounds the inequities experienced by Gypsies and Travellers in life, as members of these communities consistently die at a younger age (Baker and Leeds REC, 2005) and often in more traumatic circumstances (Parry et. al., 2004; Richardson et. al, 2007; Cemlyn et. al., 2009; Brack and Monaghan, 2007), leading to greatly exacerbated risk factors for complicated grief.

## **Risk Factors for Premature Mortality**

As highlighted in Table One, the modes of death identified are indicative of the typically poor health status, limited access to care, and lifestyle challenges Gypsies and Travellers often experience, coalescing to create high rates of premature and often potentially preventable death.

#### Health

When considering the increased risk of premature mortality amongst this community it is critically important to explore the distinct lifestyle features and predisposition to certain medical conditions which impact on their health and wellbeing. Parry et al's (2004) seminal study on the health status of Gypsies and Travellers identified the complex interplay of health inequalities and social exclusion experienced by these communities, and first recognised the significance of complicated grief as a factor influencing the health and wellbeing of Gypsies and Travellers. Although it has been acknowledged by the Department of Health, Inclusion Health Board that there are significant gaps in the evidence base pertaining to these communities (Aspinall, 2014; Greenfields and Brindley, 2016) the exacerbated risk of health problems experienced by Gypsies and Travellers have been consistently identified as rooted in multifactorial social exclusion (Cemlyn et. al., 2009). To a large extent poor outcomes are attributed to a lack of access to appropriate health services (particularly for nomadic individuals who experience frequent eviction or forced mobility) and low rates of trust in health care providers, often resulting from experiences of prejudice, discrimination in treatment and lack of cultural competence by health care staff. Research evidence suggests that many of these health inequalities result from Gypsies and Travellers experiencing economic and social exclusion, low educational attainment (including health literacy), and the poverty associated with large families and poor accommodation conditions. (Parry et al, 2004; Cemlyn et al, 2009).

Barriers to health are twofold: problematic access to health care due to mobility and the reluctance of some GPs to accept nomadic patients; coupled with environmental risks from inappropriate roadside stopping places and unauthorised sites. For example, accidental injuries (particularly to children) at dangerous locations (Beach, 1999; Greenfields and Brindley, 2016); increased risk of fire injury, and of respiratory

and communicable diseases resulting from residing in overcrowded or damp locations (Clark & Greenfields 2006; Parry et. al., 2004).

## Maternal health and risk factors for Depression and Anxiety

Gypsies and Travellers are at significantly greater risk of experiencing maternal and child death (Matthews, 2008), a situation which is for most populations in the developed world an increasing rarity as a result of high quality antenatal care. While Public Health England (2015:5) reports a continuing decline in infant mortality rates over time, currently with 4.1 deaths per 1,000 live births, consistent anecdotal evidence from midwives and health practitioners working with the populations, and limited ethnicity-specific data sets (Aspinall, 2014) suggest that significant disproportionality remains for Gypsies and Travellers. The Confidential Enquiry into Maternal Deaths (Lewis & Drife 2001) found that the maternal mortality rate for women from these communities is also disproportionate when compared to the sedentary population, although no national level data exists on mortality amongst Gypsy and Traveller women as a result of limited administrative data being recorded for these ethnic groups (Traveller Movement, 2012; Greenfields et. al., 2015). In 2004, Parry et. al found that the discrepancy in outcomes and prevalence of gynaecological related tragedies continued, with infant mortality still being significantly greater than amongst the mainstream population. Of their sample, 29% of Gypsy and Traveller women had experienced miscarriage in comparison to 16% of the comparator population from diverse ethnic communities, and 17% had experienced the premature death of a child compared to 0.9% of the sedentary population.

Several studies have suggested that these high maternal and infant mortality statistics must be attributed to poor living conditions, low immunisation rates and inadequate access to pre and post-natal healthcare as a result of mobility and frequent evictions (Parry et al 2004; Baker/Leeds REC, 2005; Cemlyn et al, 2009; Maternity Alliance, 2006). Whilst there is clearly a significant and unacceptable difference in mortality rates for members of these communities these figures also need to be recognised as situated within the context of large family size and a relatively long period of childbearing, often commencing with early marriage in late teens and with late born children delivered when a woman is nearing menopause. Data indicates that within

most families, Romany Gypsy women give birth to an average of 3.5 children and Irish Traveller women 5.9 children across their lifespan, compared to 1.7 children born to a woman in the sedentary population (Cemlyn et al., 2009).

Thus household structure and demographics for many Gypsy and Traveller families resembles those of families in many lesser developed regions of the world, or common in 19th Century Britain. The stark differences in pregnancy and childbirth experience between women who are members of the 'mainstream' sedentary populations and Gypsies and Travellers, is therefore evident throughout their lifespan, with a woman potentially growing up having witnessed the premature death of siblings and her own mother, as well as having a greater risk of seeing her daughter or grandchild dying in a pregnancy related incident. In terms of bereavement, the potential for experiencing complicated grief reactions is thus clearly substantial. Moreover, despite relatively recent advances in recognition of the impacts of miscarriage, stillbirth and infant death, the duration of parental (and grandparents/siblings) long-term grief is often not fully recognised by health professionals or those close to the bereaved parents (Turton et. al., 2009; Koopmans et. al., 2013).

There is a commonly held misconception that the death of a foetus early in pregnancy or of a child in the early days after birth (particularly if a child was born with a disability) is a less significant loss than that of an older child or an adult; thus bereaved individuals in such circumstances appear to have a reduced likelihood of receiving ongoing support or recognition of their grief (Toffol et. al., 2013; Jaffe, 2014). Evidence gathered during the current study, clearly demonstrates the long-term impacts of maternal/pregnancy bereavement on wider family members:

'My baby was stillborn... I didn't realise the impact on my mother and my sister as they tried to support me. My sister has waited twelve years to have a baby [as a result of her fear], she was only ten when I lost my baby, no one explained to her, she was afraid the same would happen to her, and my mother - no one thought to ask her about the loss of her grandchild. Its twenty years since my baby died but it is only since my sister having her baby that we have talked about it and realised how much it has affected all of the family'. (Romany Gypsy woman, interview participant)

There is also a potential correlation between high rates of pregnancy related/maternal bereavement and the statistically significant greater level of depression and anxiety

found in Gypsy and Traveller women when compared to comparator groups. Bereavement is highlighted as a common catalyst for depression (RCP, 2015), with poor mental health found to be twice as common in women as men within Parry et. al.'s (2004) sample group. Indeed, it is suggestive that given the prevalence of maternal bereavement amongst this population, complicated and prolonged grief may be manifesting as psychological problems such as anxiety and depression as this interview extract reiterates:

'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' (Irish Traveller interviewee).

## Mental health

As noted above, when death occurs in the context of a close-knit kin group in which daily (or high levels of) contact exists between the deceased and their family, an overwhelming sense of loss may exist. Our findings suggest that a culture specific practice of 'not speaking about' bereavement is common amongst respondents potentially exacerbating symptoms of grief:

"If it's a member of your own family [who is bereaved], 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 [even if a shared loss has occurred, e.g. a parent or sibling]." (Traveller Woman, participant in focus group)

This internalisation of feelings and grief makes Gypsies and Travellers particularly vulnerable to poor mental health following significant loss. There is considerable anecdotal evidence (Parry et. al., 2004; Greenfields, 2008; Cemlyn et. al., 2009) that amongst Gypsies and Travellers there are strong cultural taboos associated with acknowledging concerns over mental well-being, with an expectation that people will simply 'get on with it' and men in particular dealing with distress by resorting to drink or 'going off' (see Greenfields in Richardson, et al, 2007; Greenfields, 2008). Gypsies and Travellers, particularly women, will openly discuss problems they are experiencing with their 'nerves' (Parry et al, 2004), but making other reference to mental illness

(including bereavement related depression) is overwhelmingly seen as shameful, with such difficulties typically hidden; dealt with within the family or by self-medicating with drugs and alcohol (Matthews 2008).

'They [Travellers] 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' (Irish Traveller focus group participant).

Goward et. al.'s (2006) research into the mental health needs of Gypsies and Travellers found that the majority of those interviewed felt unable to seek help within the community (a finding borne out by Greenfields, 2008) suggesting that the extended family structure can both be an advantage and disadvantage – supporting an individual at time of need *yet* hindering engagement with mental health services. Accordingly, it is difficult to accurately assess the full extent of mental health related problems experienced by Gypsies and Travellers, not least because of the widespread failure of health services to include ethnic monitoring of Gypsies and Travellers within categories of service users accessing services (Greenfields et. al., 2015).

It has long been recognised that key factors which influence mental health include the loss of a parent at a relatively early age (most notably the loss of a mother is known to have long-term effects on women's lives) and Goward et. al. (2006) and Richardson et al (2007) produce graphic evidence of such losses impacting on Gypsy and Travellers' coping mechanisms over many years.

Greenfields (in Richardson et, al, 2007 p113) interviewed a 50-year-old woman who following the loss of her mother was forced to become the family matriarch in the absence of any older women in her extended family, thus demonstrating both the intensity of her loss, and the impact that shorter life expectancy has on families when role models and supportive older generations pass away at a relatively early stage of life:

'When you lose your mother you're head of the family. You've lost your mentor so you're having to fill a pair of shoes as well as grieve a pair of shoes'

For any individual experiencing significant loss, there is likely to be a period where they require support and time to come to terms with the change in their life. In a culture where an individual is unable to openly acknowledge their grief, but is typically required

to immediately take responsibility for the needs of their wider family and who in some cases might be having to simultaneously deal with major practical issues - such as eviction or supporting young children who have lost a parent – there are clearly considerable additional risks to their mental wellbeing, not least the impact on young people who may not be fully aware of adult concerns or know the full facts of a death.

The impact of maternal mental health on the growth and development of children, as Allen (2001:16) suggests, need further consideration, as he posits that 'the roots of mental health problems [often] lie in childhood', with mothers suffering poor mental health such as depression and anxiety five times more likely to have children experiencing emotional and behavioural difficulties than do women who are psychologically well-supported (Meltzer et al 2003). Accordingly, these studies are supportive of our proposition that the impacts of bereavement may have a detrimental effect on the health and wellbeing not only of adult Gypsies and Travellers, but also on dependent children.

#### Suicide

Persistent anecdotal evidence from support workers and Gypsy and Traveller community members, supported by findings from leading Irish studies (Brack and Monaghan, 2007; Walker 2008), suggest that complicated grief may, in some cases, be implicated in the inflated suicide rates amongst Gypsies and Travellers.

There are also strong links between untreated mental illness (particularly depression) and suicide, with statistical evidence that 75% of suicides do not access mental health support services (National Mental Health Development Unit (NMHDU), 2009). Given the high prevalence of both depression, anxiety and of suicide within Gypsy and Traveller communities and their well-documented lack of access to support services (Greenfields, 2008; Cemlyn et. al., 2009; Parry et. al., 2004) it is arguable that bereavement and long-term complicated grief are the underlying causes of some suicides as well as long-term distress and mental health problems. Bereavement-related suicide has been found to be particularly prevalent in Ireland, with one third of Irish Traveller deaths attributed to unresolved grief following the recent loss of a close relative (Walker 2008). Alcohol and substance misuse was consistently found to be a precipitating factor in many of these deaths. Concurrent evidence of the significance of alcohol and substance misuse as a 'coping mechanism' in relation to bereavement-

related grief, has also been identified by Parry et al (2004); Cemlyn et al (2009) and Richardson et. al, (2007). Whilst there are evidential links between suicide and substance misuse, there is a significantly stronger correlation between unresolved grief; clusters of death within a community or individual family, poverty and social exclusion (Cemlyn et al 2009) as risk factors leading to suicide attempts.

'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 group participant).

#### Conclusion

The outcomes of this research suggests 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. 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 in facilitating community and family resilience, many other aspects of Gypsy and Traveller culture and lifestyles appear to have a detrimental effect on bereavement experiences and grief responses.

The use of alcohol and self-medication (through sharing of prescription drugs) are anecdotally frequently used as coping strategies by Gypsies and Travellers in the absence of formal or specialist bereavement support. What limited evidence exists, suggests that members of these communities who have accessed formal medical support following bereavement have routinely been prescribed medication rather than offered counselling (Richardson et. al., 2008; Greenfields, 2008), resulting in a lack of awareness of, and access to bereavement services and increasing the sense of mistrust and inequity in health care which has been reported in much of the literature.

Whilst this paper addresses our previous work and the findings from Roger's doctoral research, the recently gathered data confirms findings from earlier studies and anecdotal narratives pertaining to the impact of bereavement (specifically traumatic loss) persisting across generations within Gypsy and Traveller communities. Accordingly, we suggest that a clear need exists for improved access to tailored

services provided by culturally competent staff, which will improve Gypsies and Travellers experience of, and willingness to, access services.

The emphasis on the delivery of services by a known and trusted person who understands and respects Gypsy and Traveller culture and beliefs was reiterated throughout focus group and interview data. There was absolute agreement from all respondents that external services provision should be tailored to meet the cultural needs and beliefs of Gypsy and Traveller communities as well as a consensus that services provided by external agencies must be developed *with* the communities in partnership, to ensure that Gypsy and Traveller culture and beliefs were reflected and respected in service delivery.

Given that *all* Gypsy and Traveller respondents identified a need for access to better information on emotional support requirements, we feel confident in asserting that there is a requirement for specific, tailored services to be developed for these populations to both reduce the impact of unresolved grief on health, wellbeing and family functioning and in so doing ensure that Gypsies' and Travellers' grief is neither 'hidden' or their suffering 'forgotten' by service providers.

#### References

Allen, G. (2011) Early Intervention: The Next Steps An Independent Report to H M Government London: Cabinet Office.

Aspinall, P (2014). *Inclusive Practice: Vulnerable Migrants, Gypsies/Irish Travellers, People Who Are Homeless, and Sex Workers: A Review and Synthesis of Interventions/Service Models that Improve Access to Primary Care & Reduce Risk of Avoidable Admission to Hospital.* London: Department of Health. Available at: <a href="https://www.gov.uk/government/publications/access-to-primary-care-among-vulnerable-groups-review-of-evidence">https://www.gov.uk/government/publications/access-to-primary-care-among-vulnerable-groups-review-of-evidence</a>. Accessed 06-08-15.

Baker, M and Leeds Race Equality Council. (2005). *Gypsies and Travellers: Leeds Baseline Census 2004 -2005*. Leeds: Leeds Racial Equality Council.

Beach, H (1999) *Injury Rates in Gypsy-Traveller children*. MSc Community Child Health Dissertation Cardiff: University of Wales College of Medicine (unpublished dissertation)

Brack, J & Monaghan, S (2007). *Travellers' Last Rites: responding to death in a cultural context.* Dublin: Parish of the Travelling People.

Cemlyn, S., Greenfields, M, Burnett, S. et. al. (2009). *Inequalities Experienced by Gypsy and Traveller Communities: A Review.* London: Equality and Human Rights Commission.

Clark C & Greenfields M (eds.) (2006) Here to Stay: The Gypsies and Travellers of Britain. ,Hatfield: University of Hertfordshire Press.

Commission for Racial Equality (CRE) (2006). Common Ground: Equality, good race relations and sites for Gypsies and Irish Travellers: Report of a CRE inquiry in England and Wales London: CRE.

Crabtree, V. (2015) <u>Religion in the United Kingdom: Diversity, Trends and Decline.</u> (no place of publication): The Human Truth Foundation Available at: <a href="http://www.vexen.co.uk/UK/religion.html">http://www.vexen.co.uk/UK/religion.html</a> accessed 30.03.2017

Diacon, D, Kritman, H, Vine, J and Yafal, S. (2007). *Out in the Open. providing accommodation, promoting understanding and recognising the rights of Gypsies and Travellers*. Coalville: British Social Housing Foundation

Department of Health (DH). (2010). *Tackling Health Inequalities in infant and Maternal Health Outcomes*. London: Department of Health.

Equality and Human Rights Commission (EHRC). (2016). *Is England fairer? The state of equality and human rights in 2016.* London: EHRC.

European Roma Traveller Forum (ERTF). (2015). Factsheet of Roma/Gypsies/Travellers in the UK. Strasbourg: ERTF.

Elliot, E. (2007). Acute gastroenteritis in children', *British Medical Journal. 6 (334) pp 35–40.* 

Gilbert, K. (2002). Taking a narrative approach to grief research: finding meaning in stories. *Death Studies 26: 223-240.* 

Greenfields, M (2006). Family, Community and Identity. In: Clark, C and Greenfields, M. (eds.) *Here to Stay: The Gypsies and Travellers of Britain*. Hatfield: University of Hertfordshire Press. 28-56.

Greenfields, M (2008) 'A Good Job for a Traveller?' – exploring Gypsies and Travellers' perceptions of Health and Social Care Careers. High Wycombe: BNU/Aim Higher South East

Greenfields, M.; Cemlyn, S. & Berlin, J. (2015). Bridging the Gap between academics and policy makers: Gypsy, Traveller and Roma health and social work engagement: thematic meeting report and policy guidance from a Council of Europe/European Academic Network on Romani studies funded International seminar (December 2014). High Wycombe: BNU. Available at: <a href="http://bucks.ac.uk/content/documents/Research/INSTAL/Bridging\_the\_Gap\_Health\_and\_Social\_Care\_Report.pdf">http://bucks.ac.uk/content/documents/Research/INSTAL/Bridging\_the\_Gap\_Health\_and\_Social\_Care\_Report.pdf</a>. Accessed 30-3-17.

Greenfields, M and Brindley, M. (2016). *Impact of insecure accommodation and the living environment on Gypsies' and Travellers' health. Policy Advice to the National Inclusion Health Board.* London: DH.

Goward, P, Repper, J, Appleton, L. et. al. (2006). Crossing boundaries, Identifying and meeting the mental health needs of Gypsies and Travellers. *Journal of Mental Health* 15(3): 315-327.

Hockey, J., Katz, Z. Small, N (2001). *Grief, Mourning and Death Ritual.* Maidenhead: Open University Press.

Jaffe, J. (2014). The Reproductive Story: Dealing with Miscarriage, Stillbirth, or Other Perinatal Demise. In: Barnes, D. (ed.) *Women's Reproductive Mental Health Across the Lifespan*. New York: Springer.

Koopmans L, Wilson T, Cacciatore, J et. al. (2013). Support for mothers, fathers and families after perinatal death. *Cochrane Database of Systematic Reviews 2013, Issue 6. Art. No.: CD000452. DOI: 10.1002/14651858.CD000452.pub3.* 

Lewis,G and Drife,J. (2001) Why Mothers Die 1997 -1999: the confidential enquiries into maternal deaths in the United Kingdom 41 London: Royal College of Obstetricians and Gynaecologists Press.

Maternity Alliance (2006) *Maternity Services and Travellers*, London: Maternity Alliance

Matthews, Z. (2008) *The health of Gypsies and Travellers in the UK.* London: Race Equality Foundation.

Meltzer, H. Gatward, R. Corbin, T. Goodman, R. Ford, T (2003) *The mental health of young people looked after by local authorities in England: summary report*, London. The Stationary Office.

National Mental Health Development Unit (NMHDU) (2009) National Suicide Prevention Strategy: Annual report on progress 2008. [Online] available from:: www.nmhdu.org.uk [accessed 27.0711]

Okely, J. (1983) The Traveller Gypsies. Cambridge: Cambridge University Press. Parkes, CM, Prigerson, HG. (2010). *Bereavement: Studies of Grief in Adult Life, Fourth Edition*. Hove: Routledge.

Parry, G, Van Cleemput, P, . Peters, J, et. al. (2004) *The Health Status of Gypsies and Travellers in England: a report to the Department of Health* Sheffield: SCHARR/University of Sheffield. available from: <a href="http://www.sheffield.ac.uk/scharr/research/publications/travellers.html">http://www.sheffield.ac.uk/scharr/research/publications/travellers.html</a> accessed 11.08.2015.

Public Health England (2015). Reducing infant mortality in London: An evidence – based resource. London: PHE.

Richardson, J, Bloxsom, J. & Greenfields, M. (2007). *East Kent Sub-Regional Gypsy and Traveller Accommodation Assessment Report.*(2007 – 2012). Leicester: De Montfort University. Available at:

http://thanet.gov.uk/pdf/East%20Kent%20GTAA%20FINAL%20report%2026%20June%2007.pdf accessed 12.08.2015.

Ropers-Huilman, R. & O'Brien, N. (2015). Feminist research paradigm. In J. Bennett (Ed.), *The SAGE encyclopedia of intercultural competence (Vol. 2, pp. 333-336*).

Royal College of Psychiatrists (2015) *Bereavement*, available at: <a href="http://www.rcpsych.ac.uk/mentalhealthinfoforall/problems/bereavement/bereavement/">http://www.rcpsych.ac.uk/mentalhealthinfoforall/problems/bereavement/bereavement/bereavement/bereavement/bereavement/bereavement/bereavement/</a>. <a href="http://www.rcpsych.ac.uk/mentalhealthinfoforall/problems/bereavement/bereavement/bereavement/bereavement/">http://www.rcpsych.ac.uk/mentalhealthinfoforall/problems/bereavement/bereave

Ryder, A, and Greenfields, M (2010). 'Roads to Success: Routes to Economic and Social Inclusion for Gypsies and Travellers' (A report by the Irish Traveller Movement in Britain (ITMB) funded by Big Lottery Research). London: ITMB.

Shear, MK., Simon, N, Wall, M. et al. (2011). Complicated grief and related bereavement issues for DSM-5. *Depression and Anxiety*, 28(2), 103-17

The Traveller Movement. (2012). *Inclusion and ethnic monitoring of Gypsies and Travellers in the National Health Service*. London: The Traveller Movement. Available at: <a href="http://www.travellermovement.org.uk/wp-content/uploads/2014/01/Inclusion-and-ethnic-monitoring-of-Gypsies-and-Travellers-in-the-National-Health-Service-report.pdf">http://www.travellermovement.org.uk/wp-content/uploads/2014/01/Inclusion-and-ethnic-monitoring-of-Gypsies-and-Travellers-in-the-National-Health-Service-report.pdf</a>. Accessed 30.3.2017.

Toffol E, Koponen P and Partonen T (2013). Miscarriage and mental health: results of two population-based studies. *Psychiatry Research*, 205:151–158.

Turton, P. Evans, C & Hughes, P (2009) Long-term psychosocial sequelae of stillbirth: phase II of a nested case-control cohort study. *Arch Womens Ment Health.* 12(1):35–41

Walker, M.R. (2008). Suicide Among The Irish Traveller Community 2002-2006. Wicklow Town: Wicklow County Council

Williams, P. (2003). *Gypsy World: The Silence of the Living and the Voices of the Dead.* Chicago: The University of Chicago Press.

.

**Acknowledgements:** The authors gratefully acknowledge the participation of the Gypsy and Traveller respondents who have taken part in this study and shared their very personal narratives with us, and the assistance of the Traveller Movement,

Leeds GATE and One Voice for Travellers in assisting with critical feedback and support in recruiting participants throughout this project.

We are also particularly grateful to the Faculty of Society and Health, Buckinghamshire New University for financial support provided through the Research Challenge fund to assist in time away from teaching duties for the primary author and the development and printing of bereavement-support materials designed for use with children.

**Statement of Ethical Approval/Consents**: All research undertaken in association with this on-going project have been subject to full ethical review and approval by Buckinghamshire New University's Faculty of Society and Health Ethics Panel. Participants have given informed consent for the inclusion of data and quotations to be used in any publication arising from this study. The names and information of all participants has been anonymised in line with best practice and the approvals granted by the Ethics Committee for this study.

**Disclosure Statement:** There is no financial interest or benefit which will accrue to the authors from the application of this research.

For the purposes of this text and in line with current cultural and policy usage in the UK, 'Gypsies' is used to refer to members of the English Romany community whilst 'Travellers' is used both to refer to ethnic minority groups such as Irish and Scottish Travellers and as a generic term to encompass all other groups of *nomadic* people, or those of nomadic heritage. In the current UK usage this definition excludes the people identified as 'Roma' who are classified in UK policy documents as migrant populations from Europe who share a cultural/linguistic heritage with English (Romany/Romanichal) Gypsies but who by dint of their relatively recent migration are perceived of as 'other' than Gypsies and Irish/Scottish Travellers who have a history in mainland Britain of many hundreds of years. While the use of the word 'Traveller' is not unproblematic (given its origins as an identifying marker for those nomads of Irish, Scottish and Welsh descent as well as those formerly sedentary members of the community who have adopted a nomadic way of life in the previous three generations) it is increasingly accepted as a politically inclusive term which permits all nomadic people, whatever their ethnic origins, to acknowledge some form of collective identity whilst recognising the structural constraints and common experience of prejudice and racism encountered by all currently nomadic people as well as those who are 'ethnically' Gypsies or Travellers albeit living in housing.