

**Experiences of Vulnerability from a
Gypsy/Travelling Perspective: A
phenomenological study**

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Abstract

People can experience feeling vulnerable whenever their health or usual function is compromised and can increase when they enter unfamiliar surroundings, situations or relationships. One's experience of vulnerability can also be heightened through interaction between the individual and the society within which they live. As such, vulnerability is a dynamic concept that crosses the interface between the self and the social world. It is, therefore, a key concept for professional practice; however this complex, elusive phenomenon is ill defined within the literature.

Within studies of vulnerability it is the existential (lived) experience (emic perspective) that is the most silent in comparison to normative perspectives (etic perspective). The Gypsy/Travelling community are often normatively identified by researchers and professionals as a vulnerable group due to increased morbidity and mortality (Goward et al. 2006; Parry et al. 2007) as well as their marginalised status within society (Van Cleemput 2007; McCaffery 2009). But this tells little of the experience of feeling vulnerable by the individuals themselves, and yet without their stories and experiences how can professionals ensure that service developments meet their needs. This research addresses this gap in the evidence base by exploring the lived experience of vulnerability of a Gypsy/Travelling community.

The study consisted of two phases (a breadth phase followed by a depth phase), after the work of Todres and Galvin (2005). The breadth phase (Phase 1) consisted of narrative interviews with five Gypsies and Travellers exploring times in their lives when they had felt vulnerable. This identified the following:

- A feeling of vulnerability created by the potential or actual lack of physical travelling experience.
- Fear of the future and declining physical health.
- Being an outsider; this experience of vulnerability contained two similar but distinct variants.
 - Insider identity
 - Perception of others outside the Gypsy /Travelling community
- Vulnerability connected to the ambiguities of their historical, cultural and geographical identity.

Phase 2 explored the experience of vulnerability related to the ambiguities of their historical, cultural and geographical identity by exploring their experience of being

part of a cultural group with threatened cultural identity and heritage. The lived experience of this type of vulnerability was described by 15 participants and descriptive phenomenological analysis (Giorgi 2009) identified six constituents of the phenomenon of vulnerability:

- Vulnerability due to feeling defined and homogenised in a particular way
- Vulnerability of feeling pressurised to conform to live a particular way
- Vulnerability of feeling split in one's identity
- Vulnerability due to feeling a loss of one's heritage
- Vulnerability of feeling discriminated, persecuted and threatened
- Vulnerability of powerlessness

The findings of this study on the lived experience of vulnerability (emic) present a different perspective to vulnerability than what is already known from the literature (etic). This develops the understanding of the concept of vulnerability itself, which can enhance professional skill and knowledge when working with people who may be experiencing feeling vulnerable. In addition, this thesis illuminates a light on experiences of vulnerability of Gypsies and Travellers, largely hidden within society. This new knowledge of their stories can be used to influence policy as well as statutory services (health, education and social care). Lastly, the thesis proposes a new, novel theory to understand vulnerability, referred to as "Etemic"; a fusion between the emic and etic. It argues that it is only through an appreciation of the Etemic that services can be developed to effectively address the needs of individuals within the Gypsy/Travelling community.

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Preface

To my children Bailey and Liberty – have a dream, believe in your dream and then follow it... wherever it takes you.

For Alice.....who introduced me to a world I never knew.

“The vulnerability of another person, therefore touches us not only because in it we recognize our own vulnerability, but for reasons infinitely more profound: precisely because we perceive it as such, the “voice of Being” reaches us more powerfully from vulnerability than from anything else: its presence in our longing for Being and in our desire to return to it has suddenly, in an sense, encountered itself as revealed in the vulnerability of another” (Havel 1988; p324)

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Lastly, to each individual that shared their stories and lives with me, I hope I have done your words justice.

Author's Declaration

Please note the following parts of this thesis have been presented elsewhere;

- 1) Theoretical Perspectives of Vulnerability – published in Heaslip, V., 2013a. Understanding Vulnerability. *In*: Heaslip, V., and Ryden, J., eds. *Understanding Vulnerability; a Nursing and Healthcare Approach* Chichester: Wiley.

Chapter 1 Introduction

Dictionary definitions of the term vulnerability identify multiple perspectives. Common to all of them is the danger or threat of possible harm to a person, which could be either physical or psychological. In the context of health, Shepard and Mahon (2002) identify that vulnerability is an overarching concept which contributes to, and results from, a range of personal, family, societal and political factors. Appleton (1994) agrees, and notes that vulnerability is caused by a combination of medical, psychological, social and cultural influences. Thus it can be argued that vulnerability has to be considered holistically and contextually.

Within the context of healthcare, vulnerability is a central theme which often emerges from qualitative studies exploring experiences of ill health (Hallberg and Carlsson 1998; Koffman et al. 2009). Vulnerability has also been studied quantitatively, in order to develop vulnerability scales for both adults (Myall et al. 2009) and children (Forsyth et al. 1996; Dogan et al. 2009) to assess their individual propensity to illness. Whilst these studies are methodologically different, what they do highlight is the importance of vulnerability as a central theme within healthcare. Vulnerability is also an important concept for health practitioners, especially nurses to consider. Historically, nurses have “ministered” to vulnerable populations (Drake 1998); however contemporary nurses are also likely to encounter what are described as “vulnerable people”. As such, Barker (2005) argues that addressing vulnerability is at the heart of nursing practice. Indeed the statutory body of nursing and midwifery note that people experience vulnerability whenever their health or usual function is compromised, thus vulnerability increases when they enter unfamiliar surroundings, situations or relationships (Nursing Midwifery Council 2002). Barker (2005, p.5) has expanded upon this to note that within healthcare a host of situations can “herald” vulnerability for a person, including becoming a patient as this often incorporates a loss of identity.

Vulnerability is also an integral concept within social care (Penhale and Parker 2008), as many individuals who are vulnerable require ongoing support from statutory social services. An international study by Parker et al. (2012) exploring social work curricula from a number of social work programmes across the world

identified that vulnerability was a core theme within all of the programmes. This focus on vulnerability within social care is endorsed in the Health and Care Professional Council Standards of Proficiency for Social Workers (2012; p7) who state social workers must “understand the need to protect, safeguard and promote the well-being of children, young people and vulnerable adults”.

There are health implications of vulnerability (Table 1), which can affect the individual both physiologically and psychologically. Therefore, it is important that both health and social care practitioners have a depth of understanding regarding what vulnerability is and how they, in their professional role, can ameliorate prolonged experiences of vulnerability.

Table 1 Health Implications of Vulnerability

Health implications of Vulnerability (Rogers 1997)	
Physiological effects of vulnerability	Psychological effects of vulnerability
Fatigue	Helplessness
Muscular tension	Loss of control
Urinary frequency	Lowered self esteem
Weight loss	Fear
Depression	Embarrassment
Anorexia	Loss of self-worth
Accident prone	Desperation
Acne	Powerlessness
Insomnia	Inability to express feelings
Back Pain	Anger
GI distress	Isolation
Menstrual irregularities	Uncertainty
	Anxiety/worry
	Inability to concentrate
	Weakness

Aside from the importance of health and social care practitioners having a good understanding of vulnerability, it is also vital that they are able to listen to accounts of people who have experienced feeling vulnerable. The importance of listening to individual patient experiences within the health service is being recognised much more nationally. This is largely due to the increased focus upon this as a political agenda, especially in service development and delivery (Department of Health 2008a). The document ‘Creating a Patient-led NHS’ (Department of Health 2005a; p8) recognised that good practice included:

- Respecting people for their knowledge and understanding of their own experience...and how it impacts upon their life.
- Ensuring people always feel valued by the health service and are treated with respect, dignity and compassion.
- Understanding that the best judge of their experience is the individual.

A lack of choice can also induce vulnerability; central to this is the perception an individual has of the control they have, in that the more control they perceive they have, the less vulnerable they feel (Rogers 1997). In healthcare, choice is limited as the health service remains largely service rather than needs-led, although this is being challenged by the National Health Service (NHS) constitution (Department of Health 2009b). Despite this constitution, there is evidence that the NHS is failing to put patients first (Department of Health 2008a; Parliamentary and Health Service Ombudsman 2011.; Government. 2012).

In addition, it can be argued that vulnerability is a poorly understood concept. The difficulties related to the understanding of the concept lie within the lack of research studies in this area, largely due to the difficulties encountered in doing research with vulnerable groups (Rogers 1997). In addition, where research has been carried out there appears to have been little critical exploration as to why different factors have been identified as being important to vulnerability. There is little examination of the phenomenon of vulnerability itself; what it means and what it constitutes. To date, only one study has been found which sought to explore the lived experience of vulnerability using phenomenological methods. This empirical research study was conducted by Leroux (2007) who explored clients' experience of vulnerability in therapy and the therapeutic relationship. The current study has similarities to the work of Leroux as it is also interested in the lived experience of vulnerability; however the context is much broader in that it wishes to explore the phenomenon of vulnerability experienced by a community group. The group chosen as the focus for the research is Gypsies and Travellers as they are often externally identified as a vulnerable group (etic perspective of vulnerability) by health and social care services, due to their poor health status (Goward et al. 2006; Parry et al. 2007), and difficulty accessing services (Cemlyn 2000b). However, these studies provide an external, normative perspective on the vulnerability of Gypsies and Travellers and tell us little of their lived experience of this phenomenon.

This study addresses this gap by soliciting the communities' lived or emic experience of vulnerability, a perspective which is currently missing within professional literature. These lived experiences of vulnerability can then be used to enhance practice by providing the patients' voice as required in the political drivers for the NHS and social care. Hearing individual accounts can lead to new insights into another's experience of the world; these insights can then be used to enhance practice and service development to ensure that services truly meet the needs of the individuals they serve.

1.1 Structure of the research report

The literature review (Chapter 2) locates the study within the wider health and social care literature and current evidence base. It presents some theoretical perspectives of vulnerability and explores each of these in relation to the Gypsy/Travelling community. The chapter concludes by presenting both the aims and objectives of this particular study. In chapter 3, the overarching methodology is presented locating the study within qualitative research as well as articulating the rationale for the breadth and depth study. For ease of navigation of the readers, the component methods of phases 1 and 2 have been articulated separately. Phase 1 method (breadth phase) is articulated in chapter 4, in which rationale for narrative interviews are presented as well as highlighting particular issues in this phase associated with recruitment and sampling. The findings of Phase 1 are then presented in chapter 5 and these are presented as life-world stories congruent with the philosophical tradition of phenomenology. Chapter 6 articulates a detailed account of the methods employed in Phase 2 (depth phase), exploring the data collection and analysis using the descriptive phenomenological method proposed by Giorgi (2009). The findings of Phase 2 are then presented (Chapter 7). Chapter 8 discusses the findings of both Phase 1 and 2 within the wider evidence base, exploring and highlighting where contributions to new knowledge or understandings have been identified. This chapter also presents the devised Etemic perspective of vulnerability, articulating why this new way of perceiving vulnerability is needed within health and social care. The chapter concludes with recommendations for policy makers, schools, health, social care and the criminal justice service as well as making recommendations for further study. Key to descriptive phenomenological research is the ability to be able to put one's current knowledge, beliefs and thoughts aside (through the process of bracketing) in order to learn something new, yet at the end of the thesis there was a

desire to have the opportunity to include my reflections, my new learning, so this has been added as “my story about collating their story” in chapter 9. Throughout this thesis the reader will be introduced to many new terms, especially when referring to language used by Gypsies and Travellers. In order to explain these terms the thesis includes a glossary (Chapter 11).

This chapter commenced by defining vulnerability, highlighting the importance of its contextual nature. It identified why the concept of vulnerability is important to consider in both health and social care by exploring the long-term health implications of prolonged experiences of vulnerability. Yet it also recognised the lack of exploration of vulnerability as a concept itself. This chapter also introduces the importance of hearing individual stories and accounts of people’s experiences within both health and social care, highlighting this as a key political driver within the NHS and social care. Lastly, the chapter provides the reader with a clear structure of how the thesis is presented.

Chapter 2 Literature Review

2.1 Introduction

This chapter commences by defining what is meant by the terms vulnerability and Gypsy/Traveller and explores why an understanding of vulnerability is important within the context of health and social care. It introduces the reader to the concepts of the etic and emic perspective of vulnerability and explores how the majority of research on vulnerability comes from an etic perspective. Furthermore, it presents a thematic critical review of the literature of both vulnerability and research relating to Gypsies and Travellers, highlighting what is already known and where the gaps in the knowledge are. The chapter concludes by presenting the aims and objectives of this research study.

2.2 Definitions of Vulnerability

In order to explore the concept of vulnerability further, some clarification of its contextual nature is required. Before exploring the meaning of the term in the professional discourse it is important to examine the semantics of the word. The Latin root of the term vulnerability is '*vuln*' which means wound or '*vulnare*' meaning to wound. Pearsall (2002; p.1608) defined vulnerable as being 'exposed to being attacked or harmed, either physically or emotionally'. Whereas Sykes (1982; p.1205) defined it as "that which may be wounded, susceptible of injury, exposed to damage by weapon, criticism". Common to all of these, is the notion of harm which could be either physical or psychological, as well as a danger or threat to the person. However, what is interesting to note is that the term vulnerable is actually an adjective; therefore to be vulnerable one must be vulnerable to something. However, in the context of health and social care, vulnerability is often used to describe particular groups in society such as older people, people with disabilities, people from black or ethnic minorities or people with mental health issues. Using the word vulnerability in this way focuses upon it being a plural noun (Clark 2007). Its use as a collective adjectival noun has tended to ascribe certain diminishing and negative characteristics to a whole group. Furthermore it is presented in a homogenous way which ignores individual differences and experiences. This focus of vulnerability is often linked to susceptibility of risk, yet Little et al. (2000) argues for a distinction between the terms, noting that susceptibility reflects an objective

assessment of risk of something happening whereas vulnerability recognises the subjective element of suffering associated with the experience of that happening.

The scientific use of the term vulnerability has its roots in geography (Füssel 2007; p.1608) and natural hazards research (Galea et al. 2005). However, interest in the concept of vulnerability has grown and is central to many differing areas such as ecology, poverty and development as well as health. In the context of health, Shepard and Mahon (2002) argue that vulnerability is an overarching concept which contributes to, and results from a range of personal, family, societal and political factors. This identifies a much wider, more holistic perspective than the dictionary definitions, which tend to focus upon individual characteristics of being liable to harm. Appleton (1994) agrees and notes that vulnerability is caused by a combination of medical, psychological, social and cultural factors. Thus it can be argued that vulnerability has to be considered holistically and contextually.

A concept analysis of vulnerability by Purdy (2004) identified the defining attributes to vulnerability as susceptibility, chance and openness. The empirical referents were lack of barrier, exposure or without protection. Susceptibility was the main antecedent identified, and consequences were disadvantage, harm, wounding or loss. Whilst the majority of consequences were seen as negative, it was also identified that this allowed for the potential of opportunity which could be positive (Purdy 2004). What this suggests, is that vulnerability can be seen both positively and negatively; however, within healthcare the majority discourse is to view vulnerability negatively, as something that professionals must strive to eradicate.

2.3 Definitions of Gypsy/Traveller

Gypsies and Travellers are one of the oldest minority ethnic communities in Britain (Greenfields 2007). The history of Romany Gypsies in Britain can be traced back to 1515 (Bowers Undated), and Roma and Romani group origins are thought to be Indian as their language can be traced back to Sanskrit and Romani (Van Hout and Staniewicz 2012). It is thought that the term Gypsy comes from “Egyptian”, a name given to them by the settled population due to their dark complexion. By 1530 the first Egyptians Act was passed which was designed to regulate the movement of

nomadic individuals by stopping further immigration and forcing those present to leave within sixteen days or risk imprisonment or deportation. This Act was followed by numerous others throughout the sixteenth to eighteenth centuries which sought to remove Gypsies from Britain (Greenfields 2007). Indeed, Grönfors (1982) argues that the only way Gypsies survived during centuries of oppression was to remain as obscure as possible. In contrast, Irish Travellers are an indigenous and distinct minority native to Ireland (Van Hout and Staniewicz 2012).

The numbers of Gypsy/Travellers in the United Kingdom (UK) is relatively small; the Office for National Statistics (2014) identified that there are 58,000 Gypsies and Travellers in England and Wales. It was only in the 2011 Census that for the first time Gypsies and Travellers were identified as a distinct ethnic group. These figures are significantly less than that proposed by Rhodes (2005) who estimated that there are around 300,000 Gypsies and Travellers in Britain. Reasons for this huge gap between the estimated and actual figures may be due to concerns that Gypsies and Travellers have of being identified in light of their historical persecution and therefore chose not to self-disclose. McCaffery (2009) argues that this invisibility is an example of their extreme marginalisation within society. In addition to Gypsy/Travellers who were born in the UK there is an increasing number of Eastern European Roma who are relocating to the UK.

A broad definition of Gypsy/Traveller by Okely (1983) might be “not gorgi”. Gorgi being a term used by Gypsies to refer to individuals within the settled community, whereas for Irish Travellers, the term used to refer to individual outside the Travelling community would be ‘countryperson’. The legal definition of a Gypsy was first set out in the Caravan Sites Act (1968, p.11). This definition stated that the term "Gypsy" referred to:

"persons of nomadic habit of life, whatever their race or origin, but does not include members of an organised group of travelling showpeople or persons engaged in travelling circuses travelling together as such".

This definition reflects the diversity of individuals under the umbrella term Gypsy/Traveller. It must be remembered that the Gypsy/Travelling community is not a homogenous group but consists of differing types of Gypsies and Travellers

including New Age Travellers, Irish Gypsies, Scottish and Welsh Gypsies, Showmen and Roma Gypsies. As such Lawrie (1983) denotes the term “travelling people” to encompass this diversity of groups which share a lifestyle of living in caravans and moving about the country. The current legal definition (Select Committee on Office of the Deputy Prime Minister: Housing 2004; p21) defines Gypsies and Travellers as:

"Persons who wander or travel for the purpose of making or seeking their livelihood (not persons who move from place to place without any connection between their movements and their means of livelihood)"

This definition focuses on lifestyle rather than ethnicity and includes Gypsies and Travellers as well as New (Age) travellers. However there are problems associated with this definition, in that it assumes all Gypsies and Travellers are currently nomadic. Gypsy site policy also pathologizes the nomadic lifestyle of Gypsies and Travellers, resulting in a shift in the accommodation used by Gypsies and Travellers. Van Cleemput (2007) and Brown and Scullion (2009) both note the difficulties experienced by Gypsy/Travellers in obtaining planning permission for private caravan sites, even though there is insufficient provision of both private and rented caravan sites. This coupled with Gypsies and Travellers being frequently evicted from unauthorised sites has resulted in many Gypsy Travellers having to settle in bricks and mortar. It is estimated by Clark and Greenfields (2006) that about 50-75% of the Gypsy and travelling population are now living in conventional housing. It also has to be questioned whether living in settled accommodation removes the ethnic status of a Gypsy/Traveller. Romany Gypsies and Irish Travellers are both recognised and protected under the 1976 Race Relation Act (amended by the Race Relation Act 2000, Equalities Act 2010), and Scottish Gypsies are protected under the Race Equality Scheme (2008) which further supports the ethnic origins of these communities.

It was decided that this research would not focus upon New Age travellers who choose the nomadic lifestyle rather than it being part of their cultural heritage. Therefore, the definition of a Gypsy/Traveller used for the purpose of this study was that of Morris and Clements (2001; p.7) who denoted:

“Gypsies whether English, Scottish, Welsh, or Irish Travellers; whether mobile, of limited mobility or no longer living in a mobile way of life but settled in housing or caravans on public or private sites”.

2.4 Gypsy/Traveller Culture

As Gypsies and Travellers are a distinct cultural group some understanding of their cultural identity and values are required. Whilst the number of qualitative studies with the Gypsy/Travelling community is small (Van Cleemput et al. 2007), the work that has been undertaken has typically been from an ethnographic perspective. A key study by Okely published in 1983, in which the researcher lived amongst Gypsies and Travellers for considerable periods of time during the 1970's. This ground breaking study illuminated some of the differing cultural values of this community.

The Gypsy/Travelling community places significant importance on family (Jesper et al. 2008) and being close to and staying with one's family unit. This notion of family goes beyond that of a nuclear family of offspring and parents but includes the wider extended family of siblings, parents, grandparents as well as cousins and second cousins. This results in many Gypsies and Travellers living close to or alongside these extended family units (Wetzel et al. 1983).

Within Gypsy/Travelling culture here are clear gender distinctions with regards to sexual taboos (Wetzel et al. 1983). Un-married women are rarely left alone with a man and whilst it is okay for men to have sexual intercourse before marriage this is a great taboo with regards to women who are expected to be virgins (Okely 1983). Women within the Gypsy/Travelling community typically marry earlier than women outside the community and this is often linked to their roles within their community as wives and mothers. Once married, wives are subordinate to their husbands and their role within the community is to be responsible for the cleaning of their homes and the rearing of children (Okely 1983). A core aspect of Gypsy/Travellers culture is cleanliness (Vivian and Dundes 2004) and Gypsy/Travelling women take great pride in their homes often cleaning them extensively on a daily basis. Divorce is very uncommon in the community as it is largely frowned upon seen as bringing shame to the families concerned. As well as their roles within the family, Gypsy

women often have worked extensively outside of the community, such as selling and hawking (Okely 1983). Okely (1983) argues this was because women were seen to provide a link between the Gypsy community and gorgi society in that they were less likely to be arrested and were often very successful in obtaining money and goods from the gorgi community.

This attention to cleanliness is not just located within their homes. Jesper et al. (2008) identified that attention to physical cleanliness is equally as paramount. Within American Romani culture there is the notion of both purity (*wuzho*) and pollution (*marimé*), in which the human body is divided into half, the upper body being pure whilst the lower is polluted (Vivian and Dundes 2004). There must always be a separation between the pure and the polluted. In the UK, the notion of pollution relates to both a physical and symbolic distinction between the inside and outside of the body (Okely 1983). Symbolically, Okely (1983) identifies that the outer body is the public self, that which is shared and visible to the gorgi community. This public self, she argues, really serves as the protective covering of the hidden, pure, inner self who incorporates the hidden, secret Gypsy, to be kept private and hidden from the gorgi. Whereas physical pollution links to aspects of the outer body such as hair, skin, dirt and bodily waste which are all potentially polluting if introduced back into the inner body. Therefore anything consumed and therefore introduced to the inner body must be clean, thereby having a distinction between dirty (*'chikli'*) and polluted (*'mochadi'*) (Okely 1983:81). In order to avoid *mochadi* then food eating utensils must never be washed in a bowl that is also used for washing the hands, rest of the body or clothing (Okely 1983). Therefore it is common to see multiple bowls used within a Gypsy caravan each with a specific focus; in addition, it is unlikely to see a toilet in a caravan as this would lead to *mochadi*.

Perceptions of health and illness are also different within the Gypsy/Travelling community. A study of Roma in Lasi and Cluj (Dumitras et al. 2013) identified that disease can be viewed mystically, as a punishment from God or a curse which leads individuals who are unwell to become excluded from the community through a fear of catching the disease. In contrast, in the UK, a study by Dion (2008) identified that illness was not necessarily a punishment; instead she noted a degree of fatalism with regards to health and illness irrespective of current health behaviour. However, both studies identified a tendency not to access medical advice, preferring

to seek advice from others within the community or to utilise herbal or traditional treatments that had been passed down through the generations. Highlighting that Gypsies and Travellers tend not to access external medical support until it is absolutely necessary typically when they were much more physically unwell (see section 2.8.1.1). Okely (1983) identifies that Gypsies and Travellers prefer to remain at home whenever possible when unwell as hospitals are concentrations of gorgi disease. In addition, she argues that Gypsies believe that the gorgi are condemned as *mochadi* because they fail to distinguish between the inner and outer body (Okely 1983). She therefore concludes that Gypsies will seek to be admitted to hospital when they are believed to be dying, thus the role of hospitals is to deal with the issues of the polluted body; the hospital is not for cure but for death. This makes it very challenging for a Gypsy/Travellers to be nursed in a hospital setting; they make seek to discharge themselves or simply leave against medical advice, they may refuse to eat as they cannot be reassured regarding the preparation and cleanliness of the environment so would prefer food and cutlery to be brought in from home. In addition, they would find it difficult using one bowl and flannel to wash with (as is the norm in hospital) due to their pollution perspective of *mochadi*. Hospitals also often fail to appreciate the family culture of the Gypsy/Travelling community especially with regard to visiting hours and visiting numbers. Gathering in large family groups is normal practice when a member of the family is dying or admitted to hospital (Wetzel et al. 1983). Therefore numbers of visitors can vary between forty family members for average ailment rising up to a hundred for serious health issues of senior members of the family (Vivian and Dundes 2004). This family gathering is vital within the community as families offer a support network to the ill person especially because the fear of the outsider can be prominent.

Lastly, there are huge concerns and suspicion within the Gypsy/Travelling community related to engaging with the gorgi community (see 2.8.2.1), this has arisen due to previous discrimination experienced such as the gorgi community such as removing Gypsy children and placing them into care (Okely 1983). As a result of this, outsiders are viewed with a large degree of suspicion (Bhopal 2010), and this can influence the interactions between the two communities. Jesper et al (2008) highlighted that previous research with Gypsy/Travellers has been unreliable noting that at times Gypsy/Travellers have spoken to researchers and told them anything the researchers wanted to hear in exchange for some money as well as wanting to This links to the symbolic notion of pollution (identified earlier) in which

the public outer self will tell the gorgi anything in order to remove them from the site as quickly as possible whilst keeping the inner private self of the Gypsy culture secret and hidden.

2.5 Vulnerability and Health and Social Care

Nursing and social work share common grounds in world views and paradigms (Washington and Moxley 2013). Drake (1998) highlights nurses have always historically had a role of “ministering” to vulnerable populations. Whereas social care history commenced with ministering to the poor with the Poor Law Act of 1601 (Hothersall 2010). The word minister derives from *ministra* (Latin) or *diaconia* (Greek) denoting a religious concept of service of/to others. This service to others is a common paradigm to both health and social care, reflective of their shared religious routes of healthcare and social work.

2.5.1 Vulnerability and Health

Contemporary nurses are likely to encounter what are described as “vulnerable people” during their nursing careers. Indeed the statutory body of nursing and midwives note that people can experience vulnerability whenever their health or usual function is compromised, thus vulnerability increases when they enter unfamiliar surroundings, situations or relationships (Nursing Midwifery Council 2002). Barker (2005, p.5) has expanded upon this to note that within healthcare a host of situations can “herald” vulnerability for a person, including becoming a patient as this often incorporates a loss of identity. Furthermore, there is the potential for iatrogenic vulnerability within a healthcare setting, which can be linked to the loss of power and control over one’s body influenced by the power, prestige and position held by medicine and doctors within society. Sørliie (2006) undertook a qualitative study exploring patients’ experiences of being cared for in an acute care ward, and vulnerability arose as one of the themes. The participants expressed feelings of helplessness; a fear of what was happening, confusion regarding what was going on around them and an uncertainty of their diagnosis. In addition, lack of choice can also induce vulnerability, yet in healthcare choice is limited as the health service remains largely service rather than needs led, although this is in part being addressed by the National Health Service (NHS) constitution (Department of Health 2009b) which recognises the need to put patients first. This has been recognised in a recent report by the Department of Health (Department of Health 2008a) which

identified that patients were less confident about nurses' ability to care about them as individuals, as opposed to caring for them clinically.

Spiers (2005) identifies that vulnerability is an essential concept which nurses use in the daily course of their professional work, due to its links with health and health problems. In spite of these health implications, vulnerability is a poorly understood concept, even though Barker (2005) argues that addressing vulnerability is at the heart of nursing practice. The difficulties related to the understanding of the concept lie within the lack of research studies actually exploring what vulnerability is, by studying people's actual experiences of vulnerability.

2.5.2 Vulnerability and Social Care

Just as it is in nursing, the concept of vulnerability is integral to social care. Penhale and Parker (2008) asserts that social workers work with vulnerable individuals at individual, policy and structural levels within society. An international study by Parker et al. (2012) exploring social work curricula from a number of social work programmes across the world identified that vulnerability was a core theme within all of the programmes. This focus on vulnerability was either linked to specific groups (older people, marginalised groups), violence including child protection, welfare or health and social care focus or spirituality. As social work has a remit to assist individuals to be able to participate fully in society (Gaine 2010) they tend to work exclusively with individuals and/or groups who could be considered vulnerable. As such they have an important role as advocates for such individuals and/or communities (O'Brien 2009). This is endorsed in the Health and Care Professional Council Standards of Proficiency for Social Workers (2012; p7) who state social workers must "understand the need to protect, safeguard and promote the well-being of children, young people and vulnerable adults".

2.6 Policy Context

As statutory services, both healthcare and Social Work are highly influenced by the surrounding political context. Therefore any examination of vulnerability of Gypsies and Travellers has to be considered within the wider political context of both statutory services and legalisation related to Gypsies and Travellers.

2.6.1 Hearing People's Voices in Statutory Services

The patients' voice is now becoming more powerful politically, largely due to the recognition of the importance of the patients' voice in service development and delivery (Department of Health 2008b). Within the 'Creating a Patient-led NHS' document (Department of Health 2005b; p11) good practice was seen to include;

- respecting people for their knowledge and understanding of their own experience... and how it impacts upon their life
- ensuring people always feel valued by the health service and are treated with respect, dignity and compassion
- understanding that the best judge of their experience is the individual

This commitment towards hearing individual voices has been further endorsed in the NHS Constitution (Department of Health 2009b), and more recently Liberating the NHS (Department of Health 2010; p13) which stress "Nothing about me, without me". All of these reports highlight the need for the NHS to utilise the voices of its users in assessing the quality of the care provided, recognising that individuals are best placed to judge their experiences. Service User engagement has a longer history within social care, but is still seen as integral to developing contemporary quality services (Social Care Institute for Excellence 2007). These patients' stories and experiences are now being recognised as quality indicators alongside the traditional examination of quality with regards to clinical outcomes (Care Quality Commission 2013; Commission 2013) in both health and social care and this is in part due to recent reflections of poor quality care at the point of service delivery (Francis 2013).

As identified, a key driver in statutory services is to involve individuals in developing and reviewing services. Yet critiques of this policy could relate to a view of a homogenised "patient voice". Society consists of many diverse, different individuals yet the degree to which these different voices are heard could be questioned. This may relate to the degree to which marginalised groups have the opportunity to voice their experiences and the degree to which their voices are heard. Adeagbo (2009) identifies that barriers affecting Gypsies and Travellers becoming involved include lack of time, confidence and skills as well as poor literacy level and argues for a

more diverse approach with regards to engagement that is culturally sensitive. Engagement with Gypsies and Travellers is further endorsed by the Department for Communities and Local Government (2012; p7) who published a progress report by a ministerial working group appointed in 2010 to tackle inequalities experienced by Gypsies and Travellers. This report identified twenty-eight commitments which the government were keen to address in the following areas;

- Identifying ways of raising educational aspirations and attainment of Gypsy, Roma and Traveller children.
- Identifying ways to improve health outcomes for Gypsies and Travellers within the proposed new structures of the NHS.
- Encouraging appropriate site provision; building on £60m Traveller Pitch Funding and New Homes Bonus incentives.
- Tackling hate crime against Gypsies and Travellers and improving their interaction with the criminal justice system.
- Improving knowledge of how Gypsies and Travellers engage with services that provide a gateway to work opportunities and working with the financial services industry to improve access to financial products and services.
- Sharing good practice in engagement between Gypsies and Travellers and public service providers.

This study supports this national agenda by enabling the voices of Gypsy/Travellers to be heard in a way which is sensitive to the needs of the community. Whilst also enabling those who develop services to hear the voices of a group which are traditionally seldom heard.

2.7 Search Strategy

Searches were conducted using a variety of online databases to ensure inclusivity of differing perspectives on vulnerability including British Nursing Index, Medline, CINAHL, Academic Search Premier, Global Health, International bibliography of social sciences, Social work abstracts, Int Bibliography of the Social Science, Psyche Articles and Applied Social Service Index and Abstracts (ASSIA). The search strategy was: initial index term searches using the following keywords (in the

title, abstract or keyword) 'vulnerab*', 'Gyps*', 'vulnerab* and Gyp*', 'vulnerab* and qualitative' and 'Gypsy and qualitative' (see table 2).

Table 2 Search Terms

Key concept	Alternatives	Combinations
Gypsy	Traveller Roma Showman/Showmen Showperson English Traveller Irish Traveller Welsh Traveller Scottish Traveller Romanies Gipsies	(Gyps* or Traveller* or Roma or showm*n) AND Vulnerab* (Gyps* or showm*n or showpeople) NOT (gypseum or gypsum or gypsophila or "Gypsy moth*") (Gyps* or traveler* or Roma or showm*n or Romanie*) AND Qualitative
Vulnerab*	Vulnerable populations	(Gyps* or showm*n or showpeople) NOT (gypseum or gypsum or gypsophila or "Gypsy moth*") AND Vulnerab*
Qualitative Research		("english Traveller*" or "welsh Traveller*" or "irish Traveller*" or "Scottish Traveller*") Limit= Great Britain and Scotland (Gyps* or showm*n or showpeople) NOT (gypseum or gypsum or gypsophila or "Gypsy moth*") AND Qualitative (Gyps* or showm*n or showpeople) NOT (gypseum or gypsum or gypsophila or "Gypsy moth*") AND Research
<p>*= truncation (), AND, NOT= Boolean logic "" = Phrase searching Limit = reducing the focus either geographically, or type of publication MeSH – medical subject headings (e.g. Roma came out as Romanies and vulnerable came out as vulnerable populations)</p>		

Electronic searches were performed retrospectively and commenced from the beginning of each database from 1983 to 2010. This search identified thousands of potential papers which were further sorted by relevance. For example, papers related to vulnerability to computer viruses and hacking were excluded, as were

papers related to vulnerability linked to propensity to geographical natural disasters. This process of refinement and review continued to identify papers relevant to the research thesis. In addition a search was also performed in the Index to Thesis looking for 'vulnerable and Gypsy', 'vulnerable and health' and 'Gypsy', as well as *Ethos (Electronic thesis online service)* searching for 'Gypsy', 'Vulnerable', and 'Vulnerability'. Abstracts of thesis were reviewed to explore links to the current study of vulnerability as well as developing an understanding of the concept of vulnerability. Bibliographic references of literature were also scrutinised for further relevant material. Lastly, grey literature was explored to examine policy initiatives with regards to healthcare provision within the United Kingdom (UK) as well as statutory guidance in vulnerability. Whilst the initial search was undertaken in 2010 in order to identify the gaps in the knowledge base, this was later updated in 2014 following data collection and analysis to ensure any studies undertaken between 2010-14 were also reflected in the literature review. Within phenomenological research, the researcher undertakes an initial literature review in order to locate the study and then suspends reading on the phenomena in question in order to have theoretical distance to be open to learn something new about the phenomenon. Following the searching of the literature, key research was mapped into a table using an amalgamated version of both East et al. (2009) and Mold et al. (2005) tables (Appendix 1 Vulnerability and Appendix 2 Gypsy/Traveller). This research was identified as it either examined the concept of vulnerability itself, vulnerability was explored as a key theme arising from the research or it was research on a perceived vulnerable population. The papers presented on research on Gypsies and Travellers were chosen as they linked to qualitative research undertaken with Gypsies and Travellers or research was conducted which focussed upon a statutory service.

2.7.1 Concept Analysis of Vulnerability

One paper that had a major influence on this research was a concept analysis conducted by Spiers (2000; p716). Spiers identified two main approaches viewing vulnerability, the "etic" and "emic" perspectives. The etic perspective relates to the "susceptibility to and possibility of harm". This is externally evaluated or judged by others for example healthcare practitioners, and reflects a normative perspective. This approach focuses upon groups of people and identifies that vulnerability is dichotomous; you are either vulnerable or you are not. In contrast, Spiers (2000) also identified the emic perspective which related to a "state of being threatened and a feeling of fear of harm". This perspective is identified by the individual actually

experiencing feeling vulnerable, thus is internally evaluated or judged. In this perspective, vulnerability is exactly what the person experiencing it says it is, thus it is more holistic in nature. Spiers' (2005) concept analysis commenced with a theoretical concept clarification which led to the development of a skeletal framework informed by a study based in a nursing home which led to the identification of structural features of vulnerability within an interpersonal context (Table 3).

Table 3 Concept Analysis of Vulnerability

Concept Analysis of Vulnerability (Spiers 2005; p.343)	
Attributes	<ul style="list-style-type: none"> • An issue whenever people are interested in protecting their own & others sense of self identity. • A universal aspect of quality of life that is experienced in context of threats to a sense of personal integrity or preferred social identity. • Occurs within a psychosocial-cultural context within interpersonal interaction. • Not a personal assessment of the resources in comparison to threats. It is an emic phenomenon. • Defined by human wants/desires related to social identity & self-esteem that can potentially be harmed in social intercourse. These are culturally, socially and idiosyncratically influenced. • Closely related to the concept of self-disclosure. • Awareness of vulnerability often does not take place at a conscious level of experience. • Risk is an associated concept that frequently occurs with vulnerability. However it refers to assessment of threat based on external perceptions rather than existential ones. • Addressing vulnerability in interaction is relational work.
Pre-Conditions	<ul style="list-style-type: none"> • Individuals have a sense of the type of image they would like to present in public and are interactionally competent in co-operating to negotiate that presentation. • Individuals are willing to imagine the face needs or vulnerabilities of others within a particular social context and have the interactional competency to negotiate face or vulnerability

	concerns.
Boundaries	<ul style="list-style-type: none"> • Vulnerability is a feature of interpersonal interaction. • The concept of risk comes into play when consideration of threat is based on endangerment, functional capacity and observable behaviour rather than on the experiential phenomenon. • Risk and vulnerability are often both implicated. However risk is an external evaluation whereas vulnerability is existential.

This study proposes to build upon the work of Spiers (2000, 2005) to explore the existential emic experience of vulnerability of the Gypsy Travelling Community. By focussing upon the emic perspective it will illuminate aspects of this phenomenon which have not yet been explored, developing professional understanding of the concept further.

2.7.2 Thematic Critical Literature Review on Vulnerability

In health, the term vulnerability is commonly used; it is therefore surprising that research on vulnerability itself is limited. From reviewing the literature (Appendix 1), nineteen research papers were identified; six from the UK and thirteen internationally. Yet vulnerability is written about extensively in the professional literature, often focussing upon normative-defined vulnerable groups (etic perspective).

From reviewing the qualitative studies, it is evident that many studies exploring experiences of ill health identified vulnerability as a key theme. For example, three studies exploring patient's experiences of cancer (Little et al. 2000; Koffman et al. 2009; Solveig Iversen et al. 2013) identified vulnerability as a central theme that arose from the data. Not only was this feeling of vulnerability isolated to patients, Proot et al. (2003) study explored the family caregivers' experiences of looking after family members with palliative illness at home and identified both vulnerability increasing and decreasing factors for carers, highlighting vulnerability is not a static state but in constant flux. Yet feeling vulnerable was not just located in cancer care. A study by Sørliie (2006) explored people's experiences of being cared for in an acute ward and identified three themes of which vulnerability was one. The

participants expressed feeling vulnerable due to feeling helpless, fear of their current situation, confusion regarding their surroundings and what was happening and uncertainty of their diagnosis. A further study using hermeneutic phenomenology explored a parent's lived experience of their child with cerebral palsy having surgery (Solveig Iversen et al. 2013). This study identified that parents felt dependent upon healthcare staff and expressed feeling on the edge of vulnerability; balancing between wanting to be involved, to teach staff about the specific needs of their child whilst also wishing to be de-burdened of the responsibility for the child's well-being with regards to symptom management whilst the child was acutely ill. The study highlights that trust between staff and themselves as parents was essential. It is therefore evident that vulnerability is a key issue for both health and social care practitioners who will be supporting these individuals during these periods. Methodologically, the study by Solveig Iversen et al. (2013) also identified that using phenomenology enabled an insight into the parents' lived experience which had previously had been missing and argued that this better understanding of the parents' perspective could enhance joint working.

Other research regarding vulnerability has focussed upon experiences of individuals within what has been traditionally identified as a vulnerable group. For example, Stewart's (2005) study explored the experiences of asylum seekers and identified that their feelings of vulnerability can lead to a notion of a suspended identity which can be detrimental to health, and as such stressed that attention on vulnerability should not be located to individuals alone but should also examine mechanisms which may exacerbate experiences of vulnerability. This focus on wider issues affecting vulnerability was also identified by Maxwell's study (2006) who explored the impact of vulnerability on health choices in sexual health. This study concluded that if practitioners are to be effective in addressing sexual health inequalities then a wider examination of social context is vital. Other research identified within the thematic critical literature review focussed upon vulnerable communities (Clark 2007; Ahern et al. 2008). Clark's study (2007) explored experiences of young Congolese people in Uganda and emphasised that fixed categorical ideas of vulnerability (etic) do not reflect the complexity of the dynamic nature of vulnerability and argued these fixed categories can lead to a negative label being affixed to individuals without examining wider structural power implications, arguing for a need to better understand what vulnerability actually means to individuals.

Risk was another key focus within the research and this included children's perceptions of vulnerability to risky home situations (Boles et al. 2005) and perceptions of vulnerability to disease and vaccination compliance (Houtrouw and Carlson 1993). A study by Huta and Hawley (2010) explored vulnerability and depression recovery and identified that vulnerability and strength were not polar opposites, often both were apparent and had a unique relationship with well-being. This study concluded that vulnerability included both positive and negative dimensions.

Internationally, there was a greater focus on the development of vulnerability scales for both adults (Myall et al. 2009) and children (Forsyth et al. 1996; Dogan et al. 2009) (Appendix 1). Myall et al. (2009) developed a 22 item Perceived Vulnerability Scale in order to assess older people's perceived vulnerability to depressive symptoms and general well-being and identified that these could be attenuated in older adults who possess a strong sense of coherence and positive attitude towards life. Within the focus on children, international research (Forsyth et al. 1996; Gleason and Evans 2004; Boles et al. 2005; Dogan et al. 2009) has focused upon developing a mechanism to assess both adults and children's perceptions of vulnerability to illness as this has been demonstrated to have an impact upon child development. Whilst all of these papers identified a desire to develop a scale to measure vulnerability, none of them defined vulnerability, nor had there been a critical examination as to why different factors had been identified as being important to vulnerability.

Few studies explored the use of the term vulnerability in healthcare; one such study by Appleton (1994) explored health visitors' perceptions of vulnerability in relation to child protection and identified a lack of consensus and clear definition of the term. In contrast, Abley et al. study (2011) compared perceptions of vulnerability between older people and health and social care staff and identified there was a difference between older people's and professionals' construction of vulnerability. For older people, vulnerability was an emotional response to being in a specific situation with little or no control, whereas professionals' defined vulnerability in light of risk associated with old age. Clearly identifying that professional and personal perspective of vulnerability can be very different and this may be due to differing definitions of vulnerability.

Surprisingly, within the literature there appears to be little examination of the concept of vulnerability itself, what it means and what it constitutes. This is supported by Little et al. (2000) who argue that vulnerability has been studied less than it merits considering that narratives of patients and healthcare workers often identify it as either a repeated theme, or a central theme in the health transaction. To date, only one study sought to explore the lived experience of vulnerability. Using descriptive phenomenology, Leroux (2007) sought to explore clients' experience of vulnerability in psychotherapy and the implications for this in the therapeutic relationship. This study identified 11 themes, six of which were common to all clients (Table 4).

Table 4 Findings of Leroux study

Findings by Leroux (2007)	
Themes	Themes expressed by all/ some participants
1. Vulnerability as a generalised life experience	All
2. Vulnerability as an experience specific to the therapeutic encounter	All
3. Vulnerability with others	All
4. Vulnerability as a feeling of being exposed	Some
5. Vulnerability in time & boundaries	Some
6. Vulnerability as a feeling of being left alone	Some
7. Physical descriptions of vulnerability	Some
8. Vulnerability as a dilemma	All
9. Vulnerability as a tension	All
10. Vulnerability in the power dynamic	Some
11. Vulnerability in the meeting or 'mis-meeting'	All

From reviewing the study by Leroux, it can be identified that shared aspects of the phenomenon of vulnerability included that vulnerability was a life experience that tended to occur in the context of others which led them to feeling a tension or dilemma. This is perhaps unsurprising as the study sought to understand something more about the client's experiences of vulnerability within the context of a therapeutic encounter with a psychotherapist.

As it can be seen the majority of research studies on vulnerability has tended to focus upon the "etic" perspective of vulnerability exploring groups who are at risk of harm or susceptible to harm, largely in order to identify practice solutions to ameliorate these difficulties. In contrast the "emic" perspective (lived experience) is very silent within the literature, and this may possibly reflect the bio-medical

discourse within healthcare, of a focus upon science to cure. Yet this discourse has to change, in response to the increased focus on hearing the individuals' voices within health and social care both in the development and review of services.

2.7.3 Thematic Critical Literature Review on Gypsy/Travellers

From reviewing the literature (Appendix 2) the literature review identified forty-two research papers which cited Roma, Romani, Gypsy or Traveller in their title or key words, nineteen from the UK and twenty-three internationally. From reviewing the UK studies the majority of them were qualitative (n=14) and many reasons were cited for this including poor literacy and a cultural heritage of storytelling, therefore interviews chosen as being more culturally sensitive. Other research included mixed methods (n=2) or quantitative (n=3). Five of the papers reviewed focussed specifically on Irish Travellers and three of these were written by the same author (Van Hout 2010a, 2010b, 2011), and of those studies two were on the same topic of substance misuse. The greatest majority of studies focussed on both Gypsies and Travellers on a variety of issues such as; health (Papadopoulos and Lay 2007; Parry et al. 2007; Van Cleemput et al. 2007; Dion 2008; Van Hout 2010b, 2011; McGorrian et al. 2012; Pinkey 2012), criminal justice service and violence (Meek 2007; Allen 2012) liaison with statutory services (Cemlyn 2000a; Van Hout 2010a; Smith and Ruston 2013) and education (Myers et al. 2010; Bhopal 2011a, 2011b).

The studies exploring health identified clear distinctions between the life expectancy of Gypsies and Travellers and the settled community. The major study in England undertaken by Parry et al. (2007) identified that Gypsies and Travellers have poorer physical and mental health than their matched sex counterparts in the settled community. This may be in part due to fatalistic beliefs regarding health and ill health which can make health promotion initiatives more challenging (Van Cleemput et al. 2007; Dion 2008). The study by McGorrian et al. (2012) identified that Gypsies and Travellers tended not to access primary healthcare services, rather they had a higher usage of accident and emergency departments. The study also highlighted that the participants expressed poorer healthcare experiences and concluded there needed to be a greater focus on communication and engagement with the Gypsy/Travelling community in order to address their health needs. There appeared to be a common theme in many of the studies which explored health or healthcare services (Papadopoulos and Lay 2007; Van Cleemput et al. 2007; Dion 2008; Van

Hout 2010a) highlighting that there needs to be better cultural awareness on behalf of staff working with Gypsies and Travellers.

Within the education sector, there appeared to be a common theme which identified racism as a particular challenge for young Gypsies and Travellers and this occurred not only from their peers but also school staff (Bhopal 2011a, 2011b). In these two studies it was apparent that staff felt challenged when working with young Gypsies and Travellers largely due to a lack of cultural awareness regarding the community. The study concluded that because the majority of Gypsies/Travellers are “white” then negative behaviour towards them due to their cultural identity was not perceived as being racist.

It was clear from a number of studies on health (identified above), social care (Allen 2012) and the Criminal Justice Service (Meek 2007) that there is a lack of cultural awareness amongst professional staff of Gypsy/Traveller culture and this is negatively impacting upon the way in which staff work with individuals within the culture. This results in poorer experiences of services by individual Gypsies and Travellers, which is often compounded by cultural and structural factors, for example policies and procedures which are also not culturally sensitive as the majority of these are written by professionals in the settled community.

Of the twenty-three international research papers, again the greatest majority of the studies conducted was qualitative research (n=16), followed by quantitative (n=6) and mixed methods (n=2). The largest focus of the research was on health (Kelly et al. 2004; Kelly et al. 2006; Monasta et al. 2008; Pavlič et al. 2011; Vukovic and Nagorni-Obradovic 2011; Colombini et al. 2012; Kolarcik et al. 2012; Amirkhanian et al. 2013; Cook et al. 2013b, 2013a; Dumitras et al. 2013; Eklund Karlsson et al. 2013; Roman et al. 2014), healthcare (Bodner and Leininger 1992; Rechel et al. 2009; Janevic et al. 2011; Cook et al. 2013b, 2013a) and education (Horvai 2010; Masseria et al. 2010; Flecha 2013; Rosário et al. 2014). Of those written on health; four were focussed specifically upon sexual health and three of these (Kelly et al. 2004; Kelly et al. 2006; Amirkhanian et al. 2013) were conducted by largely the same research team.

The findings of some of the international studies mirror those studies conducted in the United Kingdom. It is evident that Gypsies and Travellers experience worse health levels not only in the UK but also internationally (Masseria et al. 2010). A

systematic review undertaken by Cook et al (2013a) exploring health outcomes and access to health services of Roma between 2003- 2012 identified a significantly higher mortality and morbidity rate. International studies also identified a largely fatalistic view to health (Dumitras et al. 2013; Roman et al. 2014) which was linked to spiritual beliefs about God. Similarly to the UK, barriers to accessing healthcare were also identified and these included both physical barriers, due to a lack of financial resources but also psychological barriers due to poor cultural awareness by professional staff (Colombini et al. 2012) and racist practices (Janevic et al. 2011). A study by Kolarcik et al. (2012) comparing social support, life satisfaction and hopelessness of Slovak Roma and non-Roma identified that Roma adolescents reported higher levels of social support and life satisfaction as well as higher levels of hopelessness. This study highlights that often life experiences are not binary opposites but often reflect a complexity of experiences.

2.8 Theoretical Perspectives of Vulnerability

It was evident from undertaking the critical literature review (research, non-research papers and grey literature) that vulnerability is a multifactorial concept which has to be viewed contextually. During this review themes emerged as to the differing theoretical perspectives on vulnerability, see figure 1.

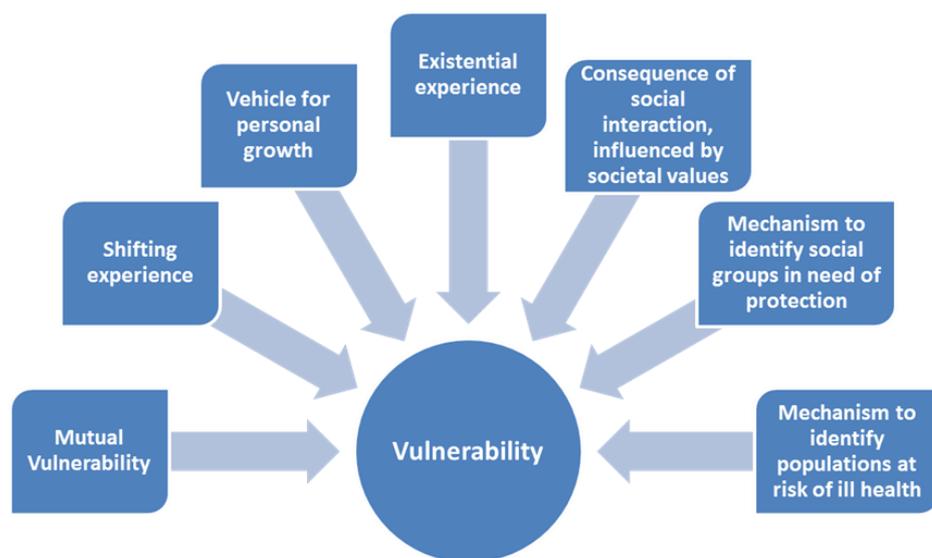


Figure 1 Theoretical Perspectives of Vulnerability (Heaslip 2013a)

Each of these theoretical perspectives of vulnerability will now be examined in turn. Firstly, their individual contribution to understanding vulnerability shall be explored including an exploration of the strengths and limitations of each of these individual perspectives. Secondly, where relevant, these differing theoretical perspectives will be considered in the context of the Gypsy/Travelling community.

2.8.1 Vulnerability as a mechanism to identify populations at risk of ill health

The prevailing discourse on vulnerability identifies vulnerable populations as “social groups who have an increased relative risk or susceptibility to adverse health outcomes.....as evidenced by morbidity and premature mortality” (Flaskerud and Winslow 1998; p.69). Linked here is the notion of risk and harm, indeed almost all uses of the term vulnerable in nursing reflects epidemiological principles of population-based relative risk. As such, population groups defined as vulnerable include the old (Spiers 2000; Rydeman and Törnkvist 2006), poor (Spiers 2000; Furumoto-Dawson et al. 2007), children (Clark 2007; Furumoto-Dawson et al. 2007; Hewitt-Taylor and Heaslip 2012) and mentally ill (Spiers 2000) and ethnic minorities (Pitkin Derose et al. 2007). Harrison (2008) argues that the reductive and clinical nature of standard biomedical science has led to a perspective that vulnerability is perceived as a problem to be solved rather than as an inherently significant condition of existence. This has resulted in a drive for action in order to ameliorate the experience of vulnerable groups by society either through public health action or by other statutory guidance. However, it must be remembered though that the concept of vulnerability is hugely influenced by society (Peternalj-Taylor 2005). Therefore, the identification of vulnerable groups often reflects the societal values and beliefs of the day. This can be explained using Giddens’ structuration theory which recognises that social structures are reshaped and changed by human agency, as well as structures shaping human agency (Giddens and Sutton 2013). Thus, societal perspectives of who are vulnerable are co-constructed by social structures such as health and social care and those vulnerable individuals in turn further shape those structures through the identification and generation of policies to meet individual needs.

Spiers (2000) argues that reducing vulnerability to epidemiological terms reduces the vision of the world, as it does little to understand why these groups may experience vulnerability. Yet this perspective continues to present the dominance of

a biomedical approach to health, and this is in contrast with my perspective on contemporary humanistic nursing ideology which recognises the need to understand the client's perspective. This can be achieved through an appreciation of the lived experience of vulnerability which seeks to understand what is happening to the person who has experienced it. For example, older people are often identified as a vulnerable group due to an increased likelihood of morbidity and mortality (Spiers 2000; Rydeman and Törnkvist 2006), yet it has to be questioned whether vulnerability is an inevitable consequence of ageing. It can be argued that ageing is not a dichotomous experience, but an individual one. Research by Myall et al. (2009) exploring perceived vulnerability on depressive symptoms and perceived general well-being in older people identified that a perception of vulnerability was attenuated in older adults who possessed a strong sense of coherence and positive attitude towards life, thereby identifying that not all older people perceived themselves as vulnerable.

2.8.1.1 Gypsy/Travelling Community and Health

Inclusion Health (Aspinall 2014) identify Gypsy/Travellers as a Vulnerable community. There is evidence within the UK that the Gypsy/Travelling community experiences poorer physical health than that of the general population (Goward et al. 2006), as well as internationally (Földes and Covaci 2012; Cook et al. 2013c, 2013a). A study by Parry et al. (2007) identified that Gypsies and Travellers reported poorer health status over the preceding year than their age sex matched counterparts, and were significantly more likely to have a long-term illness, health problems or disability. There is also evidence by Goward et al. (2006) and Parry et al. (2007) that the Gypsy/Travelling community experience poorer mental health than the general population.

Not only do the community experience poorer health but research by Cemlyn (2000b) also identified that Gypsy/Travellers experienced difficulties in accessing services due to a lack of realistic and accessible information about services available and how to approach agencies. Indeed a study by Peters et al. (2009) identified that only 69% of Gypsies and Travellers were permanently registered with a General Practitioner. In addition research by Hodgins et al. (2006) identified that the travelling community were dissatisfied with health services due to inadequate information and inequitable and poorly delivered services. Yet Erlen (2006) identifies that this lack of information and lack of services could lead people to have

a heightened sense of vulnerability. This can be further perpetuated by perceived power differentials, fear, and lack of knowledge that is often experienced by minority groups. These difficulties occur due to differing cultural beliefs regarding the cause, diagnosis and healthcare treatment (Martino Maze 2004) leading to poor communication, treatment failure and frustration for both the practitioners and the clients. Research by Francis (2009) exploring healthcare staff perceptions on Gypsy/Travellers identified that often these perceptions were informed by negative media stereotypes. In addition to this, staff identified a lack of understanding of the Gypsy/Travelling culture, health needs or issues affecting the community and this reduced their ability to work effectively with them. Perhaps because of this, there is a tendency to access health advice from within the community rather than through formal healthcare providers. Ultimately Dion (2007) asserts that there is a need for better cultural awareness on the part of service providers in order to address the morbidity and mortality rates within this community.

2.8.2 Vulnerability as a mechanism to identify social groups in need of protection

One way to explore vulnerability further is to explore the notion of a vulnerable adult identified within adult protection policy and safeguarding agenda. In this example, the term vulnerability is used to identify individuals and groups at risk of harm. Within this there are three key assumptions which will be explored in light of the *No Secrets* definition of a vulnerable adult (Department of Health 2000). The first assumption relates to normative social values, in which the term vulnerable describes people who are not able to function adequately in a socially desirable way (Spiers 2000). This is apparent in reviewing the definition of vulnerable groups provided by *No Secrets* (Department of Health 2000; p.8-9) which identified a vulnerable adult as “Anyone aged 18 years + who is or may be in need of community care services by reason of mental or other disability, age or illness and who is or may be unable to take care of him/herself”. As such, groups of people identified as vulnerable under the *No Secrets* document included older people, people with learning disabilities, people with physical disabilities, traumatic brain injuries or acquired brain damage and people with mental health problems. This definition first and foremost focuses on vulnerability being inherent to the individual and residing with the individual rather than identifying some of the wider social forces.

The second assumption is related to risk of harm or endangerment, thereby leading to societal development of authoritative professional definitions of the level of endangerment that warrants intervention. With respect to the *No Secrets* document the definition of a vulnerable adult included “.....who is or may be unable to take care of him/herself, or unable to protect him/herself against significant harm or serious exploitation” (Department of Health 2000; p.9). The last assumption relates to social sanction for intervention in order to address the deficits; in the case of *No Secrets* it could be argued that the production of national guidelines is a social sanction for action. These guidelines have also been supported by the Safeguarding Vulnerable Groups Act 2006 which was introduced in the House of Lords on 28 February 2006 and received Royal Assent on 8 November 2006. Section 59 of the Act and article 3 of the Order provides a definition of vulnerable adult (Table 5) (Office of Public Sector Information 2007).

Table 5 Definition of a Vulnerable Adult

A vulnerable adult is a person aged 18 or over who:
Is vulnerable in the context of the setting in which they are situated or the service they receive as follows;
Those in residential accommodation provided in connection with care or nursing or in receipt of domiciliary care services.
Those receiving healthcare.
Those in lawful custody or under the supervision of a probation officer.
Those receiving a welfare service of a prescribed description or direct payments from a social services authority.
Those receiving services, or taking part in activities, aimed at people with disabilities or special needs because of their age or state of health.
Those who need assistance in the conduct of their affairs.

However, there are problems associated with such a perception of vulnerability and this links to the notions of “protection” and “vulnerable”, in that this perspective of vulnerability is restrictive, negative and paternalistic rooted in welfarism. This leads to stigma being associated with the term vulnerability which then becomes defined by terms such as weakness, failure, inequality, inferiority, and dependence (Batchelor 2006). In addition, Penhale and Parker (2008) assert that it also attaches a ‘victim status’ to the individual which appears to apportion blame to the individual rather than the person, agency or society responsible for it. This can be explored through an appreciation of labelling theory which recognises that labelling

represents the power structure of society in which the powerful define those who in turn are relatively powerless (Giddens and Sutton 2013). Here it can be seen that certain individuals and groups are labelled, categorised or defined as vulnerable (Table 5), with little voice or power to challenge such assumptions about them. It is only when practitioners align with a less stigmatising conceptualisation of vulnerability will they then be better equipped to interact with vulnerable populations in ways which encourages choice and openness to decisions that have a positive impact upon lifestyles and health outcomes (Purdy 2004). In 2007 the terms “protecting vulnerable adults” was superseded by “Safeguarding adults”, in part to reflect that vulnerable adults are not different people – they are about us, and that all human beings can potentially be vulnerable (Eastman 2008). The perception of the term vulnerable as patronising and disempowering to the individual concerned, was further highlighted in the consultation of the No Secrets guidance viewed in relation to abuse (Department of Health 2009a).

Another aspect that must be considered when viewing vulnerability as a mechanism to identify social groups in need of protection, has to be protecting individuals at risk of abuse within the context of research. The Framework for Research Ethics (Economic and Social Research Council 2010) identified that participants are at an increased risk if;

- The participants belong to a vulnerable group and within the context of this document a vulnerable group included children, young people, those with a learning disability or cognitive impairment or individuals in a dependent or unequal relationship.
- Research involving sensitive topics.

2.8.2.1 Gypsy/Travelling community as a group in need of protection

Peroni and Timmer (2013; 1056) highlight that the “Roma are in special need of protection” as a result of their turbulent history, which has led to them experiencing disadvantage. It can be argued that Gypsies and Travellers are at risk of discriminatory abuse within the context of statutory services due to the poor public perception of their community and issues related to institutionalised racism (Janevic et al. 2011; Gill et al. 2013; Smith and Ruston 2013). This coupled with poor cultural competence of staff (Department for Communities and Local Government 2012; Gill

et al. 2013) could lead to Gypsies and Travellers being at risk of receiving dehumanised, discriminatory care.

Within the context of research, Gypsies and Travellers would also be identified as vulnerable due to concerns with regards to literacy in the community (Okely 1983; McCaffery 2009), as well as the power imbalance due to their marginalised status within society. There is currently a lack of qualitative studies within the Gypsy/Travelling community (Van Cleemput et al. 2007), even though Weaver Moore and Miller (1999) argue that inclusion of underrepresented groups in research will assist to providing an alternative discourse within the privileged scientific literature.

2.8.3 Vulnerability as a consequence of social interaction, influenced by society values

Both vulnerability as a mechanism to identify populations at risk of ill health and as a mechanism to identify social groups at risk of abuse, largely focus upon vulnerability being inherent and residing with the individual rather than identifying some of the wider societal forces. Another way of exploring vulnerability is to examine it from a sociological perspective, thus identifying and exploring vulnerability from wider social values. For example Peternelj-Taylor (2005) defines vulnerable populations as those who are typically impoverished, disenfranchised, or who are subject to discrimination, intolerance, and stigma. This perspective is supported by Vasas (2005) who recognised the link between marginalisation and vulnerability. Marginalisation conveys a sense of disadvantage and injustice. In nursing it reflects individuals and/or groups who are peripheralized on the basis of their identities, associations, experiences and environments (Vasas 2005). A core determinant of health vulnerability at a population level is the social status of the group, as social hierarchies promote intergeneration inheritance of social status resulting in a highly systemic and deterministic fashion (Furumoto-Dawson et al. 2007). For example, any material and psychosocial stresses imposed by social inequalities impacts upon healthcare over the entire life trajectory, hence the focus of many public health programmes on children who are disadvantaged.

One example of vulnerability as a consequence of social interaction influenced by societal values is the research conducted by Stewart (2005) exploring vulnerability of asylum seekers in the United Kingdom. This study identified that participants expressed a notion of suspended identity, just having the right to breathe, living in limbo and not feeling a sense of belonging which could impact upon the psychosocial health. In addition social isolation was also identified as a core issue, this occurred due to three main reasons. Firstly, participants expressed they were physically separated from the host society (due to housing areas) which prevented social interaction; secondly, a lack of financial resources excluded them from commercial spaces. Lastly, the participants expressed feeling vulnerable in public spaces due to fear and lack of social connection, which was fuelled by negative perceptions over asylum seekers which further compounded their experience of social isolation. As a result of these the research identified that many of the participants would hide their identity due to being embarrassed of being an asylum seeker, reporting feelings of shame, thus internalising negative perceptions. This study highlights that the societal environment has a major impact upon individuals' feelings of vulnerability, especially with regards to a largely stigmatised group.

These personal factors often relate to society's tendency to pathologise the community which reaffirms them as "other", resulting in in-group/out-group identity (Brewer 1996). This occurs through the psychological process of self-categorisation theory in which individuals define themselves and others, not as unique, but in terms of a particular group (Hogg and Abrams 2007) for example settled or Gypsy. Within this process, individuals conform to the in-group norms and customs and accentuate intergroup differences between them, for example nomadic versus settled lifestyles. This can result in the minority group, in this case Gypsies/Travellers being perceived in negative, derogatory terms in order to promote a positive self-identify within one's own group and this results in the Gypsy/Travelling community experiencing discrimination (Turner 2002; Karner 2004). Indeed the Health Ambition for the South West Strategic Health Authority (2008) identified the need for improved support for the most vulnerable, who continue to experience inequality, stigma and discrimination. It must be recognised that power, discrimination and vulnerability are interlinked cyclically (Erlen 2006), in that those that experience discrimination are often powerless which increases their vulnerability. Conversely, healthcare workers, who discriminate, abuse their power. Richardson (2006) argues the need to address institutional racism in public

institutions. However in order to achieve this, the link between power and discrimination needs to be explored. Power is dynamic, moving between social networks, and any deviance from the norm is met with negativity (Hall 1999). This judgement is inbred within social networks as such; it provides healthcare practitioners with the power to become judges of people. This occurs largely through the process of discourse, which Foucault felt was integral to understanding power (Giddens and Sutton 2013). Discourses shape the way in which we view individuals, situations and the world in which we live, and are shaped through primary and secondary socialisation. These discourses, in turn, influences the language used when referring to particular individuals or groups which can further shapes or perpetuate attitudes towards those particular individuals/groups. Expert discourses are established by those in power or authority (Giddens and Sutton 2013) such as health and social care practitioners, and can only be effectively challenged by competing expert discourses.

The difficulty here is the supposition that practitioners are not influenced by discourses, for whilst regulatory bodies provide guidance that health and social care practitioners must not discriminate (Health and Care Professions Council 2008; Nursing Midwifery Council 2008), unless they are provided with opportunities to explore their perceptions and values they may not be aware that they exist. Research by Johnson and Webb (1995, p.468) exploring the impact of labelling patients identified the impact it can have upon the psychological care that clients receive, identifying that nurses do not spend as much time with these clients. The study concluded that nurses make judgements regarding the social worth of individual when balancing competing claims upon time resources, and this raises concerns especially regarding the care of marginalised groups. Ultimately, Vasas (2005) calls for practitioners to understand marginalisation in three ways; firstly, an understanding of the experiences of marginalised people which will enable practitioners to work with clients in a more meaningful way. Secondly, a need to understand the impact of social exclusion on health and well-being of clients and lastly a need to understand the process of social marginalisation in order to increase knowledge of the ways in which they can either resist or contribute to the marginalisation of clients in practice.

2.8.3.1 Marginalisation and the Gypsy/Travelling Community

The image of a Gypsy is diverse; literary discourses often present Gypsies as romantic, mysterious individuals with social freedom (Lehti and Mattson 2001), in contrast Gypsies/Travellers are also presented as folk devils. Turner (2002) examined how Gypsies and Travellers were portrayed in debates in the House of Commons and identified persistent themes of criticism and vilification, condemning Gypsies and Travellers as dishonest, criminal and dirty. It is this discourse that is also often presented in the media. Richardson (2006) explored the use of the term Gypsy/Traveller by the media and identified that they were often referred to as 'other' and 'these people'. Other media representations of Gypsy/Traveller include being work shy or wealthy tax avoiders, and menacing invaders (Okely 2014). This distinguishes the community from society, therefore they are not like 'us' and therefore do not need to be treated with respect that ordinary people would expect. Ultimately, it must be remembered that words and terms used in discourses do not passively describe a situation but interpret them. These interpretations are based upon a variety of factors including one's own social norms and characteristics (Richardson 2006). Explanations for the hatred of Gypsy/Traveller often relate to the interface between the differing cultural expectations which allows the 'othering' of a community to which one does not belong, whilst also allowing ones' own community to be seen as morally superior and 'civilised' (Greenfields 2007; p76). A discursive analysis of internet discussion forums about Gypsies in the UK by Goodman and Rowe (2014) identified that the level of prejudice that would not normally be accepted towards other minority groups was commonplace when discussing Gypsies and seen as acceptable.

In addition to personal factors, there are also structural factors that contribute to the exclusion of the Gypsy/Travelling community. These include being located on the outskirts of society which marginalises the community, further compounding the sense of "them" and "us" (Lee and Schreck 2005). The 1960 Caravan sites and Development Act introduced greater regulation over caravan sites of all kinds which resulted in the closure of many Gypsy Sites (Greenfields 2007). In 1968, the Caravan Sites Act identified that Local Authorities had a duty to provide accommodation for Gypsies and Travellers in their local area, however this duty was repealed in 1994 (LeedsGate 2014) by the Criminal Justice Act. This act abolished statutory obligation to provide accommodation and made it a criminal offence to camp on land without the owner's consent (Greenfields 2007). This made

it much more difficult for Gypsies and Travellers to maintain a nomadic lifestyle and commenced the trend for Gypsies and Travellers to move into settled accommodation (housing) due to the increased tensions faced with statutory services for pitching their wagons on unauthorised sites. Whilst opportunities to purchase land was identified by the Planning Circular 1/94 and was taken up by a large number of Gypsies and Travellers, many found themselves in difficulties with planning regulations which resulted in their land being categorised as an unauthorised site. Greenfields (2008) identifies that approximately 25% of Gypsies/Travellers living in caravans do so on unauthorised locations. The amendment to the Housing Act in 2004 (Greenfields 2007) required all local authorities with housing responsibilities to review the needs of Gypsies and Travellers in separate accommodation assessment called Gypsy Traveller Accommodation Assessments (GTAA). This highlighted a lack of Gypsy/Travellers sites, yet public opposition makes it difficult to create new permanent and transit sites which results in Gypsy/Travellers having to locate themselves on unauthorised sites and face multiple evictions and potential criminal prosecution. Greenfields (2008) estimated in 2005 that a homeless Gypsy/Traveller at an unauthorised location would wait on average 27 years to access an authorised site. Where sites are available, Van Cleemput (2007) identifies they are often of substandard quality, often with close proximity to motorways, railways, major roads, industrial estate and pits which can be hazardous to health.

Van Cleemput (2007) notes that the cultural importance of nomadism for Gypsy/Travellers is really important, and as a result of the current policy on site provision there is a strong sense of injustice that society does not value their culture and intends them to abandon their nomadic lifestyle. Therefore they perceive that they are seen as inferior through a lack of entitlement to equal cultural rights that are afforded to other groups (Van Cleemput 2007). Such forced assimilation is viewed as a threat to their identity. Giddens (1991) refers to this concept as “ontological security” which refers to self-perception and the need to be in control of one’s own environment in order to feel secure of one’s place in society. This can be threatened when there is lack of control in maintaining a secure base or environment that one can call home and when there is lack of opportunity to exercise autonomy. This is very poignant when exploring the Gypsy/Traveller community who have to shift their notions of home to reflect the majority discourse due to public policy on Traveller sites. Giddens (1991) also argues that ontological

security requires a positive view of the self in relation to others. For Gypsies and Travellers there is a strong sense that society does not value their culture and wants them to abandon their lifestyle, resulting in them perceiving that they are seen as inferior (Van Cleemput 2007). Perhaps because of this the community chooses to stay within their communities preferring not to integrate. McCaffery (2009) identifies and raises the interesting point of the Gypsy/Travelling community self-marginalising, in that they place themselves on the edge of society, living apart from and choosing not to interact with mainstream society, which can further perpetuate the “them” and “us”.

The Gypsy/Travelling community is recognised as one of the most socially excluded marginalised groups (Van Cleemput et al. 2007; McCaffery 2009), who often experience discrimination (Turner 2002; Karner 2004). Cemlyn (2000a) argues that the travelling community could be perceived as vulnerable due to these structural inequalities experienced, as well as a tendency to pathologise them which reaffirms them as other which results in increasing their vulnerability.

2.8.4 Vulnerability as a shifting experience

Archer Copp (1986) provided an alternative viewpoint (Table 6), arguing that rather than a dichotomous experience, vulnerability needed to be expressed as a continuum, upon which individuals will move depending upon the experience at that time. This is a shift away from the etic perspective of vulnerability towards recognising the contribution of the individual experience. Recognising that some individuals may be more susceptible to experiencing vulnerability due to a balance of both features inherent to the individual, as well as some of the wider forces of society. This approach adds a different dimension to the exploration of vulnerability as it recognises the complex multi fractional nature, using the analogy of an onion, vulnerability from this perspective can be seen as having multiple layers, highlighting the complexity of the term rather than perceiving it as a dichotomous experience.

Table 6 Continuum of Vulnerability

Continuum of Vulnerability (Archer Copp 1986)
<ul style="list-style-type: none">• Potentially Vulnerable – Including individuals of high risk (genetic disposition to specific diseases, low birth weight infant, teenage mother, chronic illness, and many more. It also includes individuals who may live in high crime neighbourhoods and homeless.• Circumstantially vulnerable – Including individuals during time of war, famine, poverty, trauma and expatriation.• Temporarily vulnerable – Individuals experiencing trauma, incarceration, depression, divorce or other family disruption, kidnapped victims, welfare, hostages, sexual assault and abuse.• Episodically vulnerable – Noting recurrent diseases such as AIDS, sickle cell• Permanently vulnerable – Individuals with birth injuries, hemiplegics, war wounds.• Inevitably vulnerable – Which included old age.

Whilst this approach does reflect the shifting nature of vulnerability as well as identifying the potential of acquired vulnerability due to wider circumstances, in that clients can be temporarily vulnerable it still says nothing regarding the individuals' experience of vulnerability.

2.8.4.1 Gypsy/Travellers Vulnerability as a shifting experience

Exploring this continuum of vulnerability in light of Gypsies and Travellers it can be argued that Gypsies and Travellers may be episodically vulnerable due to specific ill health, permanently vulnerable if you consider those born with disability or those that become disabled through road traffic accident and the inevitable vulnerability associated with old age, all of which are the same as individuals from the settled community. In addition some specific to the Gypsy/Traveller community include:

- Potentially vulnerable – Gypsies and Travellers are known to have a poorer health status both within the UK (Goward et al. 2006; Parry et al. 2007) and internationally (Masseria et al. 2010; Cook et al. 2013b). It is evident from research by Dion (Dion 2008), Van Cleemput et al. (2007) and Dumitras et al. (2013) that the Gypsy/Travelling community have a largely fatalistic view upon health and illness and this can make health promotion strategies more challenging with this community, which leads to higher levels of morbidity and mortality. Gypsies and Travellers that live on the roadside are officially classed as homeless under Section 175(2) of the Housing Act 1966

(LeedsGate 2014), and this increases their experiences of feeling vulnerable as it makes access to sanitation and clean water more challenging.

- Circumstantially vulnerable – an example of this related to Gypsies and Travellers could be the enforced closure of an illegal Gypsy camp (Dale Farm). This highly publicised enforced closure of the camp could be argued was traumatic for the residents as force was used to remove those living there who had barricaded themselves in. Residents on Dale Farm included both young children and older people and the violence that erupted during the closure of the site could have led to trauma as many individuals lost their homes and way of living.
- Temporary vulnerable – this can link to individual's experiences of being incarcerated. Meek's (2007) study of an individual Gypsy/Traveller highlighted some of the challenges of being in prison. These included finding being locked up difficult due to the contrast of a normal cultural value of being outside and living an outdoor life, of being segregated from his community and mixing with those outside his cultural background and lastly an increased vulnerability to be being arrested again due to having a record.

2.8.5 Vulnerability as an existential experience

A contrasting discourse identifies that all human beings are vulnerable (Erlen 2006), as part of their humanity, for human beings are never totally free from the risk of harm (Sellman 2005). Indeed anthropological features of vulnerability identify that human beings are poorly equipped physically and socially, herein lying their potential flourishing, but also their vulnerability (Kottow 2004). Thus vulnerability is a "*condition humana*" which affects us all (Kottow 2003; p.461). Within this perspective it does recognise that some groups may be more than ordinarily vulnerable due to outside factors, whilst respecting the individualistic nature of vulnerability. This had advantages as it avoids assuming that vulnerability is an inevitable consequence of gender, age, socio-economic status. Vulnerability therefore exists as a lived experience of the individual's perception of self and their resources to withstand such challenges. Identifying that vulnerability is based on the experience of exposure to harm through challenges to one's integrity. Barker (2005) equates vulnerability to an epic story painted on canvas, which includes not only the biological threat, but just as important the psychological, social and spiritual dimension of the person that are also affected. Kottow (2003, 2004) argues that a

distinction needs to be made to identify individuals who are more than ordinarily vulnerable, which he refers to as vulnerated or susceptible. In that these individuals suffer from double jeopardy; as they suffer from both an elevated risk of health problems as well as a greater likelihood of harm resulting from these problems. Kottow (2003, 2004) argues that this should be separated from vulnerability and should be referred to as susceptibility, as vulnerability is an essential attribute of humanity, whereas susceptibility is a specific accidental condition to be diagnosed and treated. Using porcelain as an analogy, Kottow (2003, 2004) argues that the vulnerable are intact but at risk similar to a fine piece of porcelain that is unblemished but highly vulnerable to damage. Whereas the susceptible are already injured, having suffering from some sort of deficiency that handicaps them, renders them defenceless and predisposed to further injury (Kottow 2003).

Spiers' (2000) emic perspective fits within the existential experience of vulnerability arguing that vulnerability is defined by the individual perceptions of oneself and of the resources to withstand challenges, therefore only the individual can define their vulnerability. Ultimately Spiers (2000) advocates an understanding of vulnerability as both an externally evaluated risk (etic view) or as an experiential state (emic). Whilst there are multiple studies exploring the etic perspective of vulnerability (Rydeman and Törnkvist 2006; Clark 2007; Furumoto-Dawson et al. 2007; Pitkin Deroose et al. 2007), and these studies have been useful in determining the health impact of social inequalities, they do little to understand the self-conceptualisations of health, threat or quality of life for these individuals. In contrast the literature is largely "silent" about the holistic health effects and lived experience of vulnerability and contains only "scattered references" (Rogers 1997, p.68). Few nursing scholars have attempted to understand vulnerability as an experiential quality of life (Spiers 2000), even though qualitative research could illuminate the experience of vulnerability from the individual perspective (Rogers 1997). Cowling (2000) argues that this occurs due to the "clinicalization" of human experience, resulting in the denial of important facets of human experience. There is increasing evidence that the human dimensions of care are being obscured by technological and specialised focus (Todres et al. 2009), and in social work by the economic, political and organisational constraints (Lloyd 2006).

In contrast to this, Galvin and Todres (2009a) advocate the notion of “nursing open-heartedness” as a central element to caring, which consists of three dimensions. Firstly is the infinity of otherness; which recognises that the meeting between nurse and patient is not simply an empathic encounter based on commonality or sameness, accepting that the other person cannot be reduced to what the nurse knows or be defined by the nurse’s own ideas. Next, is the notion of embodiment which recognises the shared vulnerable heritage in which the possibility of reversibility with the patient becomes apparent. The last dimension is related to practical responsiveness in which the authors argue that open-heartedness is very practical in that it responds from within the relational complexity of the situation rather than from a preconceived self-position. Therefore nurses need to become free from ideological or personal agenda to be able to freely respond to the situation at hand, and this includes preconceived diagnosis or routine ways of acting. Within social work, Dominelli (2002) argues that human behaviour is at the heart of professional social work practice and argues for the need for practitioners to focus and respond to individuals rather than focus upon services.

2.8.5.1 Humanisation framework

Todres et al. (2009) developed a humanisation of healthcare value framework reflecting their views on what it means to be human influenced by Husserl’s notion of the life-world (embodiment, temporality and spatiality) as well as Heidegger’s authentic “ownness” of self. Todres et al. (2009) identify that to be concerned with humanisation is to be concerned to uphold a particular view or value of what it means to be human. Within the conceptual framework are eight dimensions (Table 7) which can be used to examine the degree to which individuals are dehumanised or humanised. However they stress it is important to note that these aspects are not necessarily seen as binary opposites, instead offer a position to examine the experiences of others.

Table 7 Humanisation Framework

Conceptual framework of the dimensions of humanisation by Todres et al (2009)	
Insiderness	Objectification
Agency	Passivity
Uniqueness	Homogenization
Togetherness	Isolation
Sense-Making	Loss of Meaning
Personal Journey	Loss of Personal Journey
Sense of Place	Dislocation
Embodiment	Reductionist body

This ideology of caring led to the development of a humanising framework (Table 7) which can be used to explore both humanising and dehumanising aspects of healthcare on a continuum (Todres et al. 2009). Elements of this framework can be linked to the exploration of vulnerability, for example “insiderness” relates to the view that humans carry a view of living from the inside, so only individuals themselves can authorise what it feels for them, thus linking to an emic perspective of vulnerability. In contrast “objectification” relates to the labelling of people into objects, relating to the view of vulnerability from an etic perspective, the favoured approach when viewing vulnerability as a mechanism to identify people at risk of ill health. Next the issue of “togetherness versus isolation”; togetherness recognises the need to belong with others as an essential human trait whereas isolation links to separation from others and this relates to the exploration of vulnerability as a consequence of social interaction influenced by societal values. It is proposed that this research will use this framework in order to understand and illuminate the practice implications of the study.

2.8.6 Mutual Vulnerability

Gjengedal et al. (2013) argues that vulnerability is related to our embodied experience as human beings and therefore all individuals can be vulnerable when exposed to harm. Individuals working in health and social care are exposed to seeing people who may be feeling vulnerable due to a variety of reasons and through the nature of their work are open to working within traumatic life situations which can lead them to experience feeling vulnerable. Research undertaken by Stenbock-Hult and Sarvimäki (2011) on qualified nurses caring for older people

identified that the nurses experienced feeling vulnerable as a result of being exposed and confronted by the vulnerability experienced by their patients. In addition, research by Heaslip and Board (2012) exploring care provided to people with dementia identified factors which led to staff feeling vulnerable and this included:

- 1) Reminder of own mortality and morbidity
- 2) Recognition of the patients' humanity
- 3) Close relationships
- 4) Disease process of dementia
- 5) Bereavement

In this study staff expressed that the close relationship they had with residents in the care home whilst positive for providing high quality care meant that they engaged emotionally with the residents and it was this emotional engagement which exposed them to feeling vulnerable, especially when the resident died. In addition the unpredictable nature of the disease process of dementia meant that at times the residents could be physically and psychologically aggressive to staff and this was hurtful especially for the younger, more inexperienced staff who would take this personally. There is a danger that staff can respond to this wounding by acting inauthentically and become task rather than people orientated (Heaslip and Board 2012). Gjengedal et al. (2013) argue that it is only through being sensitive or open towards the vulnerability of others that we can act ethically and this is fundamental in the context of professional practice.

2.8.7 Positive dimensions of vulnerability

The theoretical dimensions on vulnerability presented to date have identified it as a negative experience. However Purdy (2004) and Batchelor (2006) argue that vulnerability can have positive dimensions including the opening up of new possibilities. A study by Huta and Hawley on older people (2010) identified that vulnerability is not merely the opposite of strength, indeed in many cases strengths and vulnerabilities together had a unique relationship with well-being, making incremental contributions to life satisfaction, positive affect, self-esteem and meaning. For professional staff, Stenbock-Hult and Sarvimäki (2011) identified that vulnerability can be seen as both a burden and as a resource. As a burden it is associated with being harmed and protecting oneself yet as a resource it can enable staff to have feelings of being sensitive and open emotionally which can lead to moral indignation which prompts courage to challenge poor care resulting in

personal and professional growth. A study by Leroux et al. (2007) identified that in order for positive dimensions of vulnerability to occur it required two fundamental aspects of the relationship. Firstly, that the therapists have some investment not only in the therapeutic agenda but also the client as an individual and secondly, the feeling that each share some measure of vulnerability within the relationship, thus meeting the essential requisites of the “open-heartedness” by Galvin and Todres (2009a).

2.9 Models of Vulnerability

Models of vulnerability exist in order to assist practitioners to be able to assess the degree of a person’s vulnerability. One such model is that by Proot et al. (2003) which developed from the needs and experiences of family members caring for a terminally ill person at home in the Netherlands (figure 2). The findings identified that caregivers expressed a continuous balancing between care burden and capacity to cope which they expressed as balancing on a tight-rope, thus reflecting vulnerability as a shifting perspective. This study identified vulnerability decreasing factors such as being able to continue their activities, having hope, a sense of feeling in control, and receiving good support in their caring role. In contrast, vulnerability increasing factors included the physical and mental exhaustion of increased care burden, an inability to undertake their chosen activities which perpetuated a feeling of loneliness and being isolated, insecurity of their caring role, fear regarding the future including facing death and the manner in which it would occur and a lack of support.

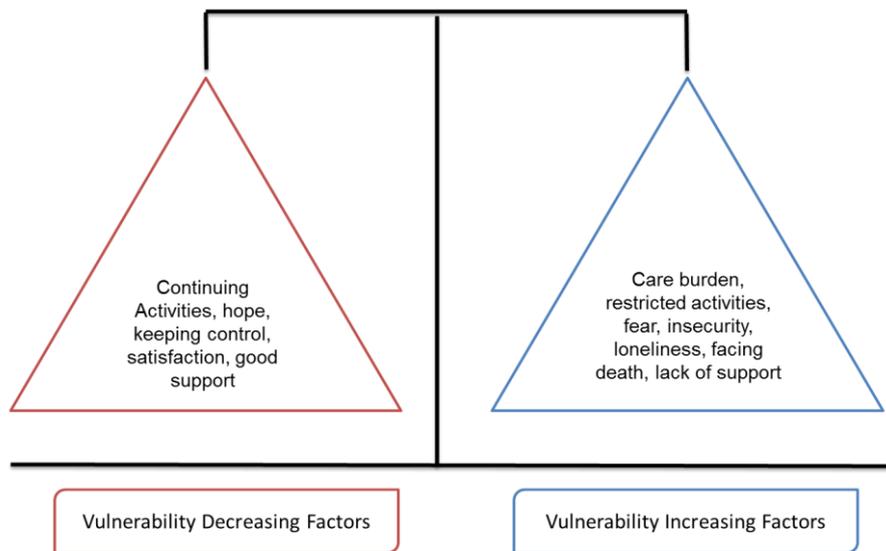


Figure 2: Model of Vulnerability (Proot et al. 2003)

This is similar to Roger's model of vulnerability (1997) who identified vulnerability as a balance between the interactions of two variables, those of personal resources and environmental supports which combined lead to vulnerability. An assessment would be made on the degree of personal resources an individual has on a continuum from few to many. Personal resources include:

- Inborn characteristics which influence health such as temperament, genetic predisposition, susceptibility to illness.
- Non-modifiable characteristics of age, gender and race.
- Acquired characteristics including trauma, disease, lifestyle and learned abilities.

Once a decision has been made on the degree of personal resources a mark is made, from this a line is drawn to the opposite apex of the triangle (figure 3).

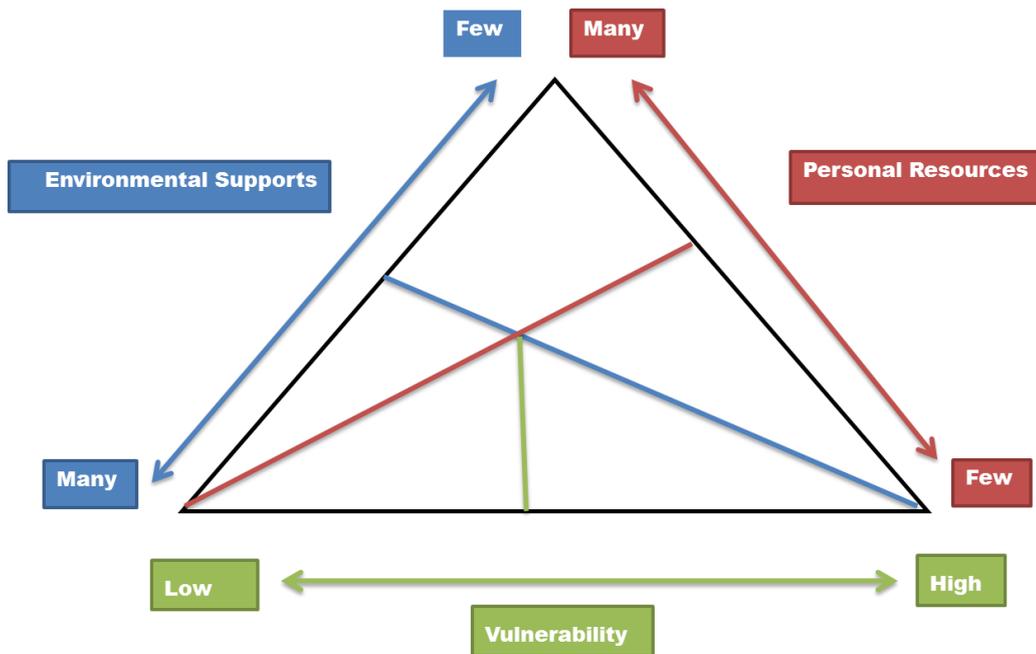


Figure 3 Model of Vulnerability (Rogers 1997)

Next, the environmental supports are assessed on a continuum of few to many. Environmental supports include:

- Immediate environment including noise, pollution.
- Broader environment including family, community and society.

Again, a decision is made regarding where on the continuum of environmental supports from few to many the individual has. From this point a line is drawn to the opposite apex of the triangle. The point where the two lines intersect would identify the level of vulnerability (figure 3).

Critiques of this model could be related to the fact that there are no units of measurement in which an individual could identify the level of personal resources or environmental supports, thus it could only be a subjective interpretation. Secondly whose interpretation would it be; the health or social care professional reflective of an etic approach or the individual reflecting the emic. Neither model has been researched to explore the validity in practice therefore it cannot be known whether they capture all essences of the phenomenon, especially in light of the lack of studies on the phenomenon itself.

2.10 Gaps in the evidence base

It was evident from reviewing the existing literature on both vulnerability and Gypsy and Travellers that this community is often perceived by both health and social care practitioners and public policy to be a vulnerable community, however whilst recognising this many questions also emerged:

- How do individuals within the Gypsy/Travelling community perceive their own experiences of vulnerability?
- Is their individual experience of vulnerability similar to their vulnerability identified by health and social care practitioners?
- What is this phenomenon of vulnerability?

This proposed research has similarities to the work of Leroux (2007) as it is also interested in the existential experience of vulnerability. However the study by Leroux explored the lived experience of vulnerability of a specific encounter between a patient and practitioner to examine the implications of this within the context of a therapeutic relationship. This study wishes to expand on the examination of vulnerability by exploring vulnerability within the context of individual's lives. It wishes to explore one particular group (Gypsies and Travellers) who are often designated by both health and social care as vulnerable and explore their lived experience of vulnerability. This aspect is currently missing in the discourse surrounding vulnerability of Gypsies and Travellers.

2.11 Aims and Objectives of the Study

2.11.1 Aims

- To understand something more about the experiences of vulnerability from a Gypsy/Traveller community perspective.

2.11.2 Objectives

- To explore the breadth of experiences associated with the term vulnerability from a Gypsy/Traveller perspective.
- To illuminate the essence of the phenomenon of vulnerability derived from detailed descriptions of experiences of vulnerability expressed by individuals within Gypsy/Traveller communities.

- To make recommendations that influence practice, theory and education for health and social care practitioners working with the Gypsy/Travelling community.

This chapter articulated the process by which the wider literature was reviewed in order to identify the current knowledge base pertaining to vulnerability and research undertaken with Gypsies and Travellers. It commenced by presenting the search strategy of the critical thematic literature review and proceeded to present the differing theoretical perspectives of vulnerability. Each of these was then explored, highlighting benefits and limitations of this approach to seeing vulnerability and where appropriate these were also considered within the context of Gypsies and Travellers. This review identified that the majority of research undertaken pertaining to vulnerability was from an external, etic perspective. In contrast, there was a lack of research undertaken exploring the lived, emic experience of vulnerability. In addition, this chapter identified that Gypsies and Travellers are identified as a vulnerable group by professionals and statutory services, yet little is known regarding their own perspective of their vulnerability. The chapter concluded by presenting how this thesis aims to address this gap in the literature by exploring the lived experience of vulnerability of individuals within a Gypsy/Travelling community. The following chapter shall outline the methodological approach chosen to undertake this research.

Chapter 3 Methodology

3.1 Introduction

This chapter outlines the philosophical approach behind the study and articulates the methods chosen in order to address the research aims and objectives. The chapter commences by summarising the aims and the objectives of the study, and the ontological and epistemological underpinnings of the work. It expands by exploring some of the ethical issues that arose during the process of conducting the research as well as identifying strategies implemented to ensure the rigour and robustness of the study. The chapter identifies that the particular approach taken by this research was twofold including a breadth and depth component; for each of these phases the specific methodological issues shall be articulated in subsequent chapters.

3.2 Qualitative Research

Before this chapter can detail the approach utilised within this research, an understanding of the philosophical tradition in which the research sits is necessary. This research is situated within the qualitative tradition. Dahlberg et al. (2008) argue that the perspective of the subjective experience is vital to understanding human experience. As such, qualitative research enables the multifaceted world to be revealed and better understood. As previously identified within the literature review, the exploration of the emic (lived) perspective of vulnerability is largely “silent” within the published literature. This research addresses this gap by aiming to understand something more about the lived experience of vulnerability within the Gypsy/Traveller community.

Ontologically, this study falls within the constructivist paradigm which assumes that reality is “...multiple and subjective, constructed by individuals” (Polit and Beck 2012:13). This study is interested in understanding the subjective experience of vulnerability of Gypsies and Travellers in order to understand their human experience of being within the world. Galvin and Teijlingen (2010) assert that qualitative research enables researchers an insider insight into different phenomena which may facilitate them to then search for meaning. The epistemological tradition of the constructivist paradigm is that knowledge is maximised through the

interaction of the researcher and participants, as such knowledge can be generated through an inductive approach by observing or participating in real settings, grounded in experience and the real world (Galvin and Teijlingen 2010).

Within qualitative research, there are multiple approaches (e.g. phenomenology, grounded theory and ethnography) each with their own distinct features. Yet they are linked by a common ontological and epistemological desire to search for meaning and an understanding of the human experience. As qualitative research utilises a bottom up/inductive approach, grounded in individuals' experiences in order to understand the phenomena being explored, it has a long history with social science researchers who wish to understand the social world. Within nursing, qualitative research methods has appeal, largely as they allow nurses to both describe and understand complex social phenomena (Streubert and Rinaldi Carpenter 2011). It is through the understanding of these experiences of others that health and social care professionals can ensure that services are reflexive to individual needs.

3.3 Phenomenology

Phenomenology (a compound of the Greek words *Phainomenon* and *logos*) is the study of human experience and the way in which things are perceived - how these appear in our consciousness (Langdrige 2007). This approach is largely attributed to the work of Edmund Husserl (1859-1938) and latterly developed further by Martin Heidegger (1889-1976). Phenomenology is primarily a philosophy with philosophical origins and goals (Giorgi 2010), however more recently it is being recognised as a research approach in its own right (Todres and Holloway 2004). Phenomenological research aims to clarify situations lived through by people in everyday life, remaining as faithful as possible to the phenomenon and to the context in which it appears in the world (Giorgi and Giorgi 2003a; P109). Whilst phenomenological research has its origins within psychological and psychotherapy research, its popularity in social science research is growing (Todres and Holloway 2010). This is because it enables the rich description of people's experiences to be illuminated so that these experiences can be understood in new, subtle and different ways (Langdrige 2007). Practitioners can then use this understanding to develop services which may make a difference to the lived experience of clients. Todres and Holloway (2010) ultimately argue that the understanding obtained through

phenomenological research can enable health and social care practitioners to become more empathetic in their response to clients, thus improving the quality of the therapeutic relationship.

Descriptive phenomenology is the most traditional approach and remains close to the philosophical tradition set out by Husserl (1859-1938). The purpose of descriptive phenomenology is to describe a phenomenon and its meanings without interpretation, explanation or construction, it is therefore important that the researcher does not make meanings that are not there or add their interpretation of events. This is achieved through a process called bracketing. Descriptive phenomenology has been adapted into a research approach largely through the work of Amedeo Giorgi. In contrast, interpretive/hermeneutic phenomenology remains close to the philosophical approaches of Heidegger, Gadamer and Ricoeur. It seeks to understand the lived experience rather than simply describe it. Ultimately both approaches focus on the lived experience of a phenomenon and either could have been used within the context of this study which was primarily concerned with the existential experience of vulnerability. However, as identified within the literature review (chapter 2) there are numerous perspectives regarding Gypsy/Traveller vulnerability and what was missing from the academic discourse was their perspective. Whilst it is recognised it was impossible to represent all of the voices of the whole Gypsy/Travelling community, it was possible to present some voices detailing individual accounts of their lived experience of vulnerability as an alternative discourse to the academic/professional perspective. It was vital that their voices were privileged and heard and descriptive phenomenology was the most appropriate methodology to facilitate this. Unlike interpretive phenomenology which seeks to use a lens by which to view and analyse the data, descriptive phenomenology seeks to describe the lived experience and, through the process of bracketing, attempts to restrict this lens.

3.4 Study Design

It has already been identified within the literature review (Chapter 2), that Gypsies and Travellers are often designated as vulnerable by health and social care professionals due to their poor physical/mental health and marginalised status within society. Yet despite knowing this, what does it tell us about their experiences of feeling vulnerable and how their feelings of vulnerability may contribute to their

health status. Without privileging and hearing the voices of individuals who have experienced this phenomenon of vulnerability how can practitioners truly have a depth of understanding of what it means. What was missing, therefore, and what this research wished to address was this gap in which their voices were heard in the professional discourse, without interpretation.

However, vulnerability is a broad concept (see 2.7 Chapter 2) which is contextually defined. In addition, as a Gorgi (name ascribed to non Gypsy by the Gypsy community) I had limited knowledge and understanding regarding the multi-faceted experiences of vulnerability of individuals within the Gypsy/Travelling community. Therefore, initially it was important to undertake a breadth study in order to gain an insight into the differing experiences of vulnerability experienced by individuals within a Gypsy/Travelling community. Inspiration was sought from a study by Todres and Galvin (2005), in which they experienced similar challenges whilst exploring the multifaceted phenomenon of caring for someone with Alzheimers. In this particular study, Todres and Galvin utilised a two-phase methodological approach (figure 4). In Phase 1 they undertook a generic qualitative study in order to understand the breadth of the experiences associated with the phenomenon of caring which enabled them to generate a broad narrative identity of the phenomenon of caring. Phase 2 developed this broad understanding further by incorporating an in-depth study of particular selected phenomena chosen from the broad narrative using descriptive phenomenological method.

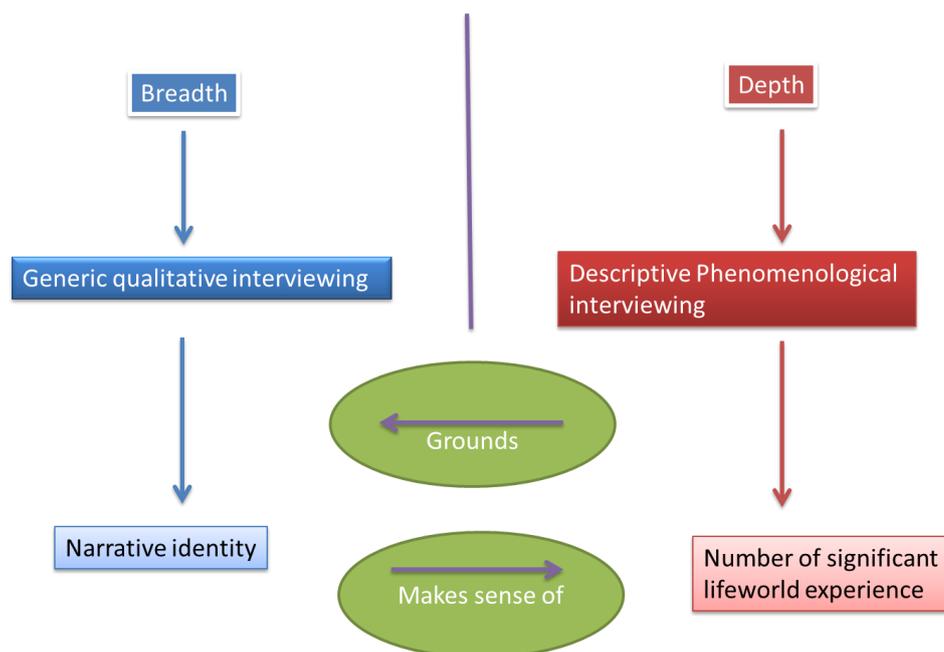


Figure 4 Methodological Approach (Todres and Galvin 2005)

This two-phase process argues Todres and Galvin (2005) enables a deeper exploration of the phenomenon of interest providing a more rounded view of the human experience. The breadth phase of the narrative identity enables the reader to make sense of the life-world experiences which are identified in the depth phase. Whilst the depths phase assists in grounding the narrative identity highlighted in the breadth phase.

Vulnerability, similar to the concept of caring is not a single phenomenon; rather it consists of several phenomena simultaneously. As such, undertaking a generic breadth phase would enable an understanding of the range of experiences of vulnerability experienced by individuals within the Gypsy/Travelling community. Through the development of the narrative identity of vulnerability it would then enable me as the researcher to identify the specific a phenomenon of interest with regards to which facet of vulnerability was most important to members of this community which could be explored further in the depth phase. Whilst this process of both breadth and depth were fundamental to this study it was also important that the research did not deviate from the grounding principles of a phenomenological study. Finlay (2011; p15) identifies six facets which she argues is central to a phenomenological project:

1. Focus on lived experience and meanings
2. Use of rigorous, rich, resonant description
3. Concerns with existential issues
4. Assumption that body and world are intertwined
5. Application of the phenomenological attitude
6. A potentially transformative relational approach

Using these facets it can be argued that even though this research undertook both a breadth and depth study, it was undertaken within the spirit of the philosophical traditions of phenomenology. The study was focussed upon the existential phenomena of the human experience of vulnerability, by exploring lived accounts from individuals within the Gypsy/Traveller community. It gathered rich descriptions of lived experiences of vulnerability in both Phase 1 and 2 and through application of the phenomenological attitude learned something new about the interaction between ourselves as physical beings and the wider world in the hope that this would lead to new knowledge and understanding about vulnerability. Lastly Finlay (2011) identifies that a phenomenological project is concerned with a transformative

approach and in order to examine this further an appreciation of the wider ethical issues and inclusion/exclusion criteria is required.

3.4.1 Inclusion and Exclusion Criteria

I sought to recruit participants from the south-west of England who fulfilled the following criteria;

- Self-ascribe as a Gypsy/Traveller. New age travellers were excluded from the study as their nomadic lifestyle is a lifestyle choice as opposed to cultural heritage.
- Be over the age of 18. Participants under 18 were excluded, largely due to ethical constraints of interviewing children.
- Participants also had to be able to communicate verbally in English due to the chosen methodological approach of interviews. Due to the sensitive nature of the research topic interpreters were deemed inappropriate by the researcher.

3.5 Ethical Considerations

As this research did not recruit through Health or Social services, approval from the Integrated Research Application system (health) or Social Care Research Ethics Committee was not required. However, the research did go through the university internal research approval system, which included submission of the research proposal, participant information sheet (PIS) and consent form (see appendix 3 and 4) for external scrutiny. Feedback from the University research committee identified a number of issues that required addressing before the research could commence and these included aspects such as provision of supervisory contact details to the PIS and further guidance of statutory obligations regarding holding of confidential information (appendix 5). In addition the reviewers sought further clarification of the term vulnerability and raised concerns as to whether the community would have an understanding of the term vulnerability. This request for further guidance was very challenging to the research which sought to understand the Gypsy/Travelling lived experience of feeling vulnerable, rather than normative/professional perspectives. This was articulated to the research committee (appendix 6), alongside evidence from a similar study exploring the lived experience of vulnerability in psychotherapy, in which the researcher identified that the participants did not experience any difficulty in understanding the term (Leroux 2009). However, other changes were

made to the participant information sheet in response to the feedback obtained and this was resubmitted to the ethical governance group (appendix 7). In light of this, ethical approval was granted for the study to continue (appendix 8). Yet, agreement from an ethical review board does not necessarily in itself constitute that the research is conducted in an ethical manner. In order to ensure that the study was ethically managed a greater review of the wider ethical issues was necessary.

Within research ethics, the four moral principles of autonomy, beneficence, non-maleficence and justice have to be considered (Tee and Lathlean 2004). Firstly, beneficence and non-maleficence explores benefits versus the risk to the participants of being involved in the research. Arguably, there are risks to all participants engaging in research which focuses on individual experiences. However, these are somewhat compounded by the real or assumed vulnerability of participants (Tee and Lathlean 2004). In addition, it has to be noted that vulnerable persons often face pressing economic needs that limit the time and energy they have available for participation (Anderson and Hatton 2000). Therefore, it was essential that any information provided to participants included a clear time requirement in order to enable the participants to decide whether they wished to be involved in the research.

Researchers undertaking qualitative research, particularly qualitative research on sensitive topics need to be able to make an assessment of the impact of the research on both the participants and themselves (Dickson-Swift et al. 2007). As this research was asking participants to share their experiences of feeling vulnerable it was important that the interviews were held in a place of the participants choosing, in order to potentially increase their feeling of safety, security and control. Interviews were conducted in a non-confrontational manner, encouraging participants to share their experiences in an environment and at a time which suited them.

During the process of obtaining consent, the researcher ensured that participants were informed that they chose what they wished to share during the interview. Informed consent is at the heart of ethical research (Department of Health 2005b), as its purpose is to ensure explicit agreement by participants to participate in the research process after receiving and comprehending information regarding the

nature of research (Hewitt 2007). In seeking consent from vulnerable people, the Economic and Social Research Council (ESRC (2010) advocate that every effort has to be made to secure active rather than passive consent. Within this research literacy is an issue with the Gypsy/Travelling community (Okely 1983), McCaffery (2009) estimates that as much as 70-80% of the Gypsy adult community are not able to read or write. Therefore whilst both written participation information sheets and consent forms were produced in order to meet the expectations of the Ethics committee, at times they were not used; instead verbal information was provided and verbal consent was obtained and recorded, a practice which has been agreed by the ESRC (2010). This method has been utilised in other studies with the Gypsy/Travelling Community (Goward et al. 2006) as well as other communities where literacy was an issue (Smith 2008). Issues related to confidentiality also form part of the consent process. Participants were informed that the taped interviews will be transcribed, and all transcripts created would be fully anonymised. However extracts may be used in the production of written reports or papers from the study, and participants were asked to verbally consent to this process. All participants were assured that any extracts used would be anonymised to ensure their confidentiality.

During the process of obtaining consent, I ensured that the participants were aware that they chose what they wished to share during the interview. My communication skills are at an advanced level, due to previous experience of working as a District Nurse seeing people in their own homes. This, I feel, benefited my research as I was aware of both the participants' verbal and non-verbal communication during the interview process. This, coupled with my professional philosophy of valuing the individual, I feel really helped me in the research as it enabled me to develop a trusting supporting environment during the interview process. During the process of data collection I shared my professional status with participants in the interests of honesty as to why I was conducting this research and what I planned to do with the findings. I acknowledge that this has both benefits and risks; the benefits in having the professional status of "nurse" meant that many of the participants trusted me and were therefore willing to speak to me. The risks were that it could introduce a sense of bias, as potentially participants could have focused upon vulnerability in healthcare. However, I do not believe that this occurred as many of the participants

did not focus upon health or healthcare when telling me their experiences of feeling vulnerable.

Lastly is the moral notion of justice. Whilst the label vulnerable may afford protection, it could also lead to a reduction in opportunities to participate in and influence the research agenda (Tee and Lathlean 2004). Indeed Sutton et al. (2003) argue that eligible volunteers from stigmatised and vulnerable populations should not automatically be excluded from participating in research, instead they should have the opportunity to know and decide about participating as part of respecting their autonomy as human beings. Failure to offer participation in research to vulnerable individuals and group could lead to only hearing privileged voices and this is against the notion of justice (Koffman et al. 2009). The purpose of research is to either add to existing knowledge about the subject in question, or develop methods for researching it (UK Research Integrity Office 2009) therefore unless research reflects the diversity of the society then the body of evidence available to policy makers would be limited (Department of Health 2005b). Pierce Dennis (1999) argues the inclusion of vulnerable groups in research expands the parameters of debate in real important ways which enables a richness of understanding. Ultimately leaving acts of social research to those who discount and ignore the paradoxes and perils that vulnerable populations face is not an ethical solution to representational dangers (Dodson et al. 2007).

3.6 Health and Safety issues raised by the study

Within any research study, consideration of health and safety issues is also important for both the researcher and the participants. The risks to participants were reduced by having the interviews in the participants' homes. However, this did not fully eradicate the risk to participants as it exposed participants to risks related to the potential of having personal, confidential information overheard by a family member. This was addressed by the participants identifying the interview time and location. In doing this, it could have potentially placed myself (the researcher) in a position of increased vulnerability. Many individuals expressed concerns about me visiting Gypsies/Travellers in their own homes and I think this is part was influenced by the negative media discourse surrounding Gypsies and Travellers as violent and aggressive. Yet I was not concerned as I had extensive experience of being a lone

worker visiting people in their own homes and as such utilised strategies developed through this previous experience such as; keeping a record of appointments, informing supervisors of proposed visits and phoning a designated contact at the start and end of interviews.

3.7 Rigour of the study

The mechanisms for establishing rigour within qualitative research relate to four key areas; credibility, dependability, confirmability and transferability. Firstly, credibility, the purpose of which is to ensure that the data presented is valid and a true representation of the participants' views. As previously identified, researching with Gypsies and Travellers can be more challenging due to the distrust that some Gypsies have with the settled community (see section 2.4). Yet the development of trust between the researcher and participants was crucial for participants to feel comfortable sharing their stories. This is potentially made more problematic due to the potential power imbalance, in that the researcher is white, female and a "Gorgi" (non-Gypsy). Anderson and Hatton (2000) identify that often researchers and participants may differ with regard to socioeconomic status, education, language and/or ethnicity and note that this can have consequences on the research process. Whilst an examination of insider/outsider debate is explored more reflexively in Chapter (9) it warrants attention here with regards to the potential impact it may have had on the rigour of the study. The notion of insider/outsider within the research process began within the fields of anthropology and sociology, exploring the extent to which the researcher was either an insider or an outsider (Merriam et al. 2001). The literature identifies that each position has both advantages and disadvantages, for example benefits of insider research are that it enables the researcher to have an initial stronger rapport with respondents as they are able to share sub-cultural gossip, anecdotes and observations (Hodkinson 2005) whilst critiques centre upon that very same closeness arguing that it can cloud the researcher's views and lead to biased findings (Innes 2009). Conversely, the strengths to outsider status are that the researcher can enter a kind of heuristic culture shock (Innes 2009) which can assist the researcher in gaining detailed/comprehensive accounts from their participants (Tinker and Armstrong 2008). Another aspect that influenced the notion of the insider/outsider in this research was that my husband's grandmother was from the showman community. This experience was shared with participants when they enquired why I was interested in the Gypsy/Traveller community and the sharing of this I feel assisted in

the development of trust. Rather than exclusive categories, Clingerman (2007) identifies that the boundaries can shift between being an adopted outsider and an insider. There were definitely moments in the research when I was both an insider and outsider, being a partial insider when sharing my grandmother-in-law's life, but still an outsider as I was not part of their community. There were also other times in which I was an insider as opposed to an outsider and these were linked to shared gender identity and motherhood, and an outsider linked to age differences between me and some of the participants (Hellawell 2006).

Often the critiques regarding the outsider debate relate to the potential difficulties in developing a rapport between the researcher and participants. As power relations are based upon a continuum, Bhopal (2009) argues they can never be fully equalised in the research process; however, to a degree the power difference can be ameliorated by researchers who are knowledgeable, sensitive, and conscientious (Peternalj-Taylor 2005). I was very open and honest with participants regarding my reasons for undertaking this research and remained faithful to the phenomenological attitude of being open to new ways of seeing vulnerability through the participants' experiences. This embracing attitude led to the participants being able to share very private, personal accounts, providing me with honest in-depth information that truly reflects their experience (thus promoting credibility of the data). This was due to my personal philosophy of valuing people which resulted in the interviews being relaxed, supportive and warm which I feel enabled the participants to feel able to share their lives with me.

Dependability and conformability of the research was established through the clear articulation of the research journey, as presented in this chapter. It was also established through sharing the process of analysis as well as the methodological journey with peers at international conferences (appendix 9), articulating rationale for decisions made. Key within this process was the discussions with the supervisory team who also took on the role of critical friends, questioning and challenging me when my articulation of the journey was not clear, as well as challenging my rationale and decisions made during the analysis of the data and in the presentation of the findings.

Lastly is the notion of transferability which relates to the extent to which the research findings are transferred from one context to another. However phenomenology is not interested in developing the universal or generalizable; rather its aim is to articulate a human dimension from one person to another. Van Manen (2013) argues that in phenomenology in developing the essence of the phenomenon you have to sense the universal, not in the sense of the universal empirically, rather the singularity or essence of the human experience which resonates with others. As such ultimately it is the reader who will decide upon the applicability of the findings to their own practice or domain. However within the findings chapters (5 and 7) as well as the discussion (chapter 8) the transferability of this research is explored in much more depth examining what was identified which can also resonate with other groups within society.

This chapter presented the philosophical approach behind the study, grounding it within human experience and ontological and epistemological tradition of qualitative research. It argued that descriptive phenomenology was the most appropriate research method to answer the research question which sought to privilege the voices of the participants. However, in recognising that vulnerability is not a singular phenomenon but rather consists of multiple phenomena it proposed that a twofold approach of a breadth and depth phase was required to explore the lived experiences of vulnerability. Lastly, the chapter critically explored some of the ethical and moral issues related to researching what could be perceived as a vulnerable group. Concluding that a failure to undertake research with what are perceived as vulnerable groups could be considered in itself unethical as it leads to a lack of understanding of the needs of these particular groups. The following chapter presents the research method of Phase 1 (breadth phase).

Chapter 4 Research Method of Phase 1 (Breadth Phase)

4.1 Introduction

This chapter details the methods used for Phase 1 (breadth component) of the study. It provides the rationale for narrative interviews articulating why this is a sound method to use when working across cultural boundaries. The chapter continues by presenting information regarding the interview schedule and the pilot interviews that occurred. Biographical information regarding the participants is presented as well as an examination of some of the ethical issues that arose at this phase. Lastly the process undertaken to analyse the data is articulated, showing you, the reader, the process by which this occurred.

4.2 Narrative Interviews

As identified in the methodology chapter (chapter 3) the purpose of Phase 1 is to develop a broad understanding of the phenomenon of vulnerability. Therefore an approach was required that would facilitate the gathering of this breadth of experiences, whilst also recognising and valuing the cultural differences between the researcher and the participants. The purpose of the interviews was exploratory and, as such, would lie within the qualitative tradition. A narrative approach to Phase 1 was identified as the most appropriate method due to the recognition of being beneficial in cross-cultural working with marginalised groups (Mattingly and Lawlor 2000; May 2001) as it enables the world of the individual to be illuminated. This is important when there are large differences between the cultural backgrounds of professionals and clients or when the group's racial background leaves them misunderstood or voiceless (Mattingly and Lawlor 2000). In addition, philosophically, this approach would focus upon the participants' lived experiences, utilise rich description which are included in Finlay's (2011) facets of a phenomenological project. In addition, and crucially to a phenomenological project, this phase would also be conducted with a phenomenological attitude, in which the research sets aside what is currently known in order to learn something new.

The process in which narratives may be collected is varied including pictures, diaries, as well as verbal. Freshwater and Holloway (2010) stress that narratives are

useful especially in exploring experiences of vulnerability as they provide the narrator or storyteller with a distance from their experience. This research chose to undertake interviews as May (2001) identified they provide rich insights into people's experiences, lives, opinions, values and feelings. This method of data collection was also chosen as it reflected the epistemological and ontological approach of the research by validating and privileging the voice of the individual (Davison 2004). In addition, it was also felt that face-face interviews were also most congruent with the Gypsy/Travelling community which has a strong oral tradition based around storytelling and songs (Lloyd and McCluskey 2008).

4.3 Interview Schedule

In phenomenologically-orientated research Giorgi (2009; p122) identifies that "what one seeks from a research interview in phenomenological research is as complete a description as possible of the experience that a participant has lived through". As such in the interview you are seeking the participants to tell you about actual experiences in their lives related to the phenomenon in question (often referred to as an experience near question). Whilst the purpose of this phase was to understand the breadth of factors using a narrative approach, I felt it was important to stay grounded within the philosophical tradition of phenomenology as it was the umbrella philosophy under which the whole research was situated. The interview was unstructured which is congruent with phenomenological interviewing as the purpose of the interview is to collate lived descriptions of the chosen phenomenon, and therefore needs to be led by the participants sharing their story. This is at the heart of the phenomenological attitude, this willingness to learn something new regarding their experience of vulnerability. May (2001) concurs that unstructured interviews are useful in enabling the meanings that individuals attribute to events and phenomena to be understood in their own terms. This was vital in this research to ensure that the breadth of experiences of vulnerability of the Gypsy/Travelling community was identified, rather than the researcher's perspective. As such, the interview schedule in phase 1 utilised the following experience near question:

"Can you talk to me about your life as a Gypsy/Traveller and describe all the times the word vulnerability applied to your life, times in which you have felt vulnerable".

Interviews were conducted within the participants' own homes in order to address the power imbalance between the participants and the researcher, placing the researcher in a vulnerable situation of being a guest in someone else's home. It also encouraged participants to feel comfortable sharing their stories. It was made explicit to the participants that there were no right or wrong answers, as I was interested in their experiences of feeling vulnerable. Participants were encouraged to continue sharing their stories during the interviews through visual prompts such as nodding, smiling as well as encouragers such as "yes", "go on", "interesting", and "please continue".

Following each interview the researcher's personal reflections were captured, promoting credibility of the research approach. Reflective thoughts were captured using a contact summary form (adapted from (Miles and Huberman 1994; p51) within one day of meeting the participant (appendix 10). The purpose of this was to capture initial thoughts regarding the participant and the interview process thus ensuring that no aspect of thoughts regarding the interview was lost. In addition to this, after each interview an audio recording was taken of the researcher's verbal thoughts and reflections on the interview, in order to capture learning from the event as well as identifying changes that could be made to the interviewing process. An example of this was following the interview with Jimmy (Irish Traveller). Whilst aware from reading that Irish Travellers prefer the term Traveller to Gypsy, and therefore during the interview when referring to Irish Travellers the term Traveller was used. However when referring to Romany Gypsies the term Gypsy was used as it is the preferred term for them; whereas Jimmy would refer to them as English Travellers. I had not really appreciated the depth to which the term Gypsy was offensive to the Irish Travelling community even though it is the preferential term used by other Gypsy groups. This impacted upon subsequent interviews with Irish Travellers as only the term Traveller was used.

4.3.1 Pilot Interview

Greenfield and Home (2006) maintain that all too often Gypsies/Travellers are over investigated for the purposes of research which fails to bring about clear change; or that the research is carried out in a manner which is either meaningless or potentially offensive which has resulted in the community reporting that they feel exploited by researchers and academics. It was therefore vital that any research approach was sensitive to the needs of the participants as well as addressing the

question posed. In order to ensure this, both the interview question and the interview process were piloted with two of the local gatekeepers who had been supporting the researcher within the study. Ideally, the pilot interview should have been conducted within the Gypsy/Traveller community; however, Bhopal (2010) stresses that word of mouth is important within this community. It was therefore essential that any questions posed would not be offensive to the community, and therefore detrimental to the future sampling of the study. Therefore, the pilot was conducted with two local clergymen who worked extensively with the Gypsy/Travelling community. They were chosen because of their expertise of working with the community, so would be ideally placed to judge whether the questions posed could be potentially offensive. Secondly, having been through the process of being interviewed they would be better placed to address any questions that could arise from the community regarding the experience and the researcher.

As illiteracy is known to be an issue with the community, I planned to read out the participant information sheet (PIS) to participants and I wished to know whether this could be perceived as offensive. The pilots identified that this was not the case. However, it did identify that the language used needed to be less official and presented in a more Gypsy/Traveller fashion. This insight was invaluable and led to me summarising the PIS verbally to participants into the main categories of confidentiality and their right to refuse to participate. I left a copy of the PIS with participants who could ask family members to read it to them (if they had difficulty reading). This was crucial to the research as I do not feel the participants would have had the same rapport with me in the interviews if I had read the whole form to them.

4.4 Sample

A purposeful sampling strategy was used as the research wished to recruit Gypsies and Travellers that had experienced feeling vulnerable at some point during their lives. The sample comprised of five Gypsies/Travellers from a mixture of backgrounds including Showman (n=1), Romany Gypsies (n=2) and Irish Travellers (n=2). In addition, the individuals I interviewed lived in a variety of geographical areas across the South West and in differing sites (council maintained site (n=1), permanent owned site (n=2), living on an unauthorised site (n=1) and living in a

house (n=1). The participants reflect a range of ages from early twenties to early seventies and consisted of both male (n=2) and female participants (n=3). Brief biographical details of the participants are presented in table 8. It is important to note here that fictional pseudonyms have been applied to each participant in order to respect confidentiality whilst also recognising them as individual human beings.

Table 8 Biographical details of participants (Phase1)

Brief Biographical details of the participants

Tommy - 50 year old Showman. Previously been married to a Gorgi and lived in a house, now divorced and living alone. Lives in a trailer in a rural community on land which he owns but does not have planning permission to reside there, as such he is currently being "chased" by the council. Tommy has electricity through a generator but accesses water through a public supply in the village green. Tommy has numerous horses and dogs for company.

Issy - Romany Gypsy. She lives in a trailer on land she owns with planning permission. She has lived in the rural village for over 30 years. Issy was married to a Giorgi and was widowed a year ago. One of her two sons lives on the site with her in his own trailer. The site has full facilities of water, electricity and sewerage.

Jimmy - 59 year old Irish Traveller. Lives with his wife, daughter (and her family) and two of his sons (with their families) on land that he owns. They have temporary planning permission and are in the process of seeking permanent planning permission for the site. The site has full running water and sewerage, although electricity is run through a generator and gas through gas canisters.

Christina - Roma Gypsy. She grew up on a council maintained site but now lives in a house. She is married to a Gorgi and has a child. Christina is a qualified nurse and works in a senior position in a private hospital.

Mary - 20 year old married Irish Traveller. She lives in a trailer on a long-term council maintained site in a town, as an addition to her parent's plot. Mary is married to an English Traveller and has a small child. Also living on the site are her parents and sister.

As with all qualitative research the sample size was small (n=5), as it was about sufficient participants to gather deep descriptions of the phenomenon. Dahlberg et al. (2008) argues that variation is more important than the number of participants as life-world research is dependent upon data which is rich in variation. The primary method of sampling strategy within descriptive phenomenology is purposeful maximum variation sampling (Langdrige 2007). The purpose of which is to seek out participants with the common experience of vulnerability, but who varied on as wide a variety of demographic characteristics as possible. Therefore, differing ages, genders and types of Gypsies/Travellers were included in the research in order to ensure purposeful, maximum variation sampling. The underpinning principle is that with such variation, it is possible (in the analytical stage) to ascertain those aspects of the experience that are invariant across perception (the essence of the phenomenon) and those that vary across perceptions (Langdrige 2007). Whilst phase 1 of the study was about developing a breadth of awareness of the phenomenon of vulnerability using narrative interviews, it was important that both phases of the research followed the philosophical principles of phenomenology.

Langdrige (2007) recognises there can be practical challenges with achieving maximum variation sampling. This can be especially so as the Gypsy/Travelling community are recognised as a “hard to reach” group within research (Greenfields and Home 2006), meaning that it is often difficult to access this community and engage them in research. The use of gatekeepers has been recognised by Bhopal (2010) as being fundamental to offering a bridge into the community. This was true in this phase as participants were recruited through Gypsy/Traveller liaison groups, networking at local and regional Gypsy/Traveller events. At times recruitment was very challenging during phase 1 of this study. This occurred due to issues regarding trust with “outsiders”, which was made more problematic due to the televised documentary series “My big fat Gypsy wedding”, which followed Traveller weddings. However, many of the Gypsies/Travellers spoken to during the process of undertaking this research expressed they had been inaccurately represented, in that the programme portrayed Irish Traveller weddings and presented them as Gypsy weddings, thus promoting a homogenised view of the community. In addition, the Irish Travellers felt that their community had also been misrepresented by the programme. During data collection there was also the highly publicised eviction of many Gypsies and Travellers from Dale Farm (Okely 2011) and this impacted upon damaging the trust the community had with Gorgis (non Gypsies). Indeed many of the participants spoken to at this time, expressed anger towards the settled

community highlighting it as just another example of how they had been “let down” by the settled community. This led to recruitment for this phase being very long and challenging. McCaffery (2009) supports that gaining access to the Gypsy/Travelling community is challenging, due to finding and making contact with people (Brown and Scullion 2009). There were many times of heightened frustration as I tried to find Gypsies and Travellers willing to speak to me. Yet I really believed in the research and was committed to ensuring that Gypsies’ and Travellers’ voices were represented in the academic discourse surrounding their vulnerability and this desire kept me going throughout that very difficult period. Weaver Moore and Miller (1999) concur it is imperative to include underrepresented groups in research to prevent further under representation within the scientific literature and body of knowledge.

4.5 Ethical Considerations

As previously identified my communication skills are at an advanced level, due to a wealth of experience of visiting people in their own homes. However, I was not fully prepared for the nature of the “Open Door” aspect of the community. Often during the one-to-one interviews (that were being audio recorded) members of the participant’s family were sometimes present or would drop by unplanned and stay and talk and this required some flexibility. I feel my background in working with people in their own homes enabled me to adapt and respond to this positively. When these situations occurred, I made sure that all individuals were aware of the nature of the research and that I was audio recording and offered to stop recording momentarily. However, this was often not deemed necessary as it was almost as if I was accepted by their family member then I was accepted by them and this again highlighted the importance of the word-of-mouth culture within the community.

4.6 Analysis

As previously identified, narrative research is not a single research approach but an umbrella term covering a range of diverse approaches (Spector-Mersel 2010). Therefore, there is no one way to analyse narrative data (Abrums et al. 2010). Lai (2010) identified that the analysis of narratives can occur in a variety of ways including:

- Explicit focus upon the content of the account – such as what happened or why from the viewpoint of the story teller.
- Explicit focus upon the form of the account – such as the structure of the plot, sequence of events and its relation to time.

As Phase 1 was to understand the breadth of experiences of vulnerability within a Gypsy/Travelling community, the analysis therefore focussed upon the content of the account rather than the way in which the narrative was told. The data was analysed using thematic analysis which Overcash (2004) notes is a common technique following the phases of thematic analysis advocated by Braun and Clarke (2006) (table 9). Utilising this approach enabled a systematic approach to the data analysis which facilitates credibility of the analysis and research process.

Table 9 Phases of Thematic Analysis

<i>Phases of thematic analysis (Braun and Clarke 2006)</i>	
Phase	Description of the process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Following the process advocated by Braun and Clarke (2006) for each interview the audio tape recording was transcribed verbatim, providing written notes with which to commence the data analysis which is consistent with the first phase (familiarizing yourself with your data Table 9). The written transcripts of the interviews were reviewed line by line and codes were identified, reflective of the second stage. Miles

and Huberman (1994) describe codes as tags or labels which are used to assign units of meaning to the descriptive data. These codes can either be descriptive straightforward categories or more complex metaphors, as the purpose of this first level coding is to summarise the segments of data. Each transcript was initially analysed in isolation and an inductive approach of allowing descriptive codes to emerge from the data was used, reflective of Phase 3 (table 9) of the process (Braun and Clarke 2006). These were then collated and summarised in a Contact Summary Form with Coded Themes as advocated by Miles and Huberman (1994) see appendix 11. All of the transcripts were then re-reviewed against these initial themes to identify relationships or themes across the interview data generated from all of the interviews undertaken (reflective of the third phase of analytical abstraction, table 9). Throughout the whole process of the thematic analysis the codes changed as more interviews were undertaken. Miles and Huberman (1994; p61) stress that this flexibility in assigning codes is important as “there is often more going on than our initial frames dream of”. This led to the identification of initial themes (Table 10).

Table 10 Initial Themes

Initial Themes	
Ontological belonging	Media representations
Community identity	Law
Ageing	Mortality
Cultural clash	Positive dimensions
Living within 2 worlds	Self-segregation
School	Eradication of Gypsies/Travellers
Discrimination	Resilience
Healthcare	Health
Erosion of Gypsy/Traveller ways	Changing times
Council sites	Not wanted
Homogenised	Belonging/community
Erosion of Gypsy/Traveller heritage	Environmental
Being assimilated	At one with nature
Free	

These themes were then analysed further on a whiteboard to explore the themes in more depth, reflective of Phase 4 (table 9) (appendix 12). This visual representation really enabled further analysis and clarification of the themes of vulnerability experienced by the Gypsies and Travellers, reflective of the last level of data analysis. However, at this stage some challenges arose as it became apparent that the themes identified did not reflect the wider philosophical perspective of the study which aimed to present the lifeworld accounts of the participants' experiences of vulnerability. Instead the themes appeared disjointed and abstract from the participants' narrative. Therefore these five themes were redefined and repackaged into four facets of vulnerability thus presenting a narrative identity of vulnerability consistent with the approach developed by Todres and Galvin (Todres and Galvin 2005) (figure 4 Chapter 3).

Initially, it was hoped to undertake all the interviews before data analysis began in order not to bias subsequent interviews. However, in reality, there was a delay in recruiting to the study and, as such, data was transcribed and analysed between interviews. In order to militate against potential bias, there was a time delay between interviews and analysis and this assisted the researcher in being open to the current recruits' experience, also the researcher entered each interview with a phenomenological attitude of "being open to learn something new". In doing so the researcher followed the same interview schedule for each interview and only asked to clarify points raised in their interview rather than seeking the participants' opinions regarding a particular aspect of vulnerability, which may have been identified in a previous interview. Miles and Huberman (1994) identify that there are benefits to analysing the data throughout the research process as data analysis is hard work. As such, they argue against leaving all of the analysis to the end as they feel it could lead the researcher to becoming sloppy in their analysis due to tiredness, which impacts upon the quality.

This chapter has presented the methods chosen for Phase 1 of this research. It highlighted why narrative interviews were the most appropriate method to use during the breadth phase due to recognition as being useful when working across cultural boundaries, as well as being congruent with the oral storytelling culture of the Gypsy/Travelling community. In addition, the chapter also presented the

rationale for the sampling strategy and some of the challenges faced during this phase of the research linked to access and recruitment. These were hampered by ongoing media representations of Gypsies and Travellers which impacted upon the trust the community had with me, an outsider. The process of analysis for the thematic interviews was detailed, highlighting why it was important to this research that the themes were presented as a narrative identity of vulnerability. The next chapter continues by presenting the findings of the breadth phase.

Chapter 5 Findings of Phase 1 (Breadth Phase)

5.1 Introduction

The findings of thematic analysis of the Phase 1 interviews are presented here. They are presented not as themes but as a narrative identity of the differing facets of vulnerability, articulating how vulnerability was experienced by members of the Gypsy/Travelling community.

5.2 Facets of vulnerability

The analysis of the five transcripts provided an enormous amount of rich, powerful and evocative descriptions on the ways in which the individuals in the Gypsy/Travelling community experienced the phenomenon of vulnerability. Four major facets of the experience of the phenomenon of vulnerability were identified;

- A feeling of vulnerability created by the potential or actual lack of physical travelling experience.
- Fear of the future and declining physical health.
- Being an outsider; this experience of vulnerability contained two similar but distinct variants.
 - Insider identity
 - Perception of others outside the Gypsy /Travelling community
- Vulnerability connected to the ambiguities of their historical, cultural and geographical identity.

5.2.1 A feeling of vulnerability created by the potential or actual lack of physical travelling experience

The first experiential experience related to a feeling of vulnerability created by the potential or actual lack of physical travelling experience. The participants articulated a close embodiment with the physical earth and this strongly linked to their perception of being free and, therefore, their identity as Gypsies and Travellers. Indeed this sense of freedom was incredibly strong and important to the participants, all of whom referred to the ability to travel. Tommy, a Showman, said, *“there’s something about the freedom of it just to be outside”* whilst Christina, a

Romany Gypsy, noted that travelling was an integral part of her life as a child growing up, *“We went away every summer in a wagon”*.

Issy (Romany), one of the older participants who had travelled extensively in a trailer as a child, spoke about missing her travelling and was really excited as she had planned a big travelling trip for the following summer, where she planned to revisit the places she had seen in her youth. She spoke of her frustration in that there were fewer opportunities to travel, due to the restrictions from central government and the impact that had on her, as well as the importance of travelling to her cultural identity:

...there is a recent saying that you can take the travelling from the Gypsies but you can't take the Gypsies from the Gypsies or travelling. Although, I've got this base here, I go off; I suppose a bit like the Aboriginals, we go walkabouts. You know, we suddenly think well I'm going to go and you go.

This feeling of missing the ability to travel was also felt by Jimmy (Irish Traveller). Like Issy, Jimmy was also older and as such could recount times in his childhood when there were more extensive opportunities to travel, he spoke of his sadness as these opportunities were now lost and his fear for his future opportunities to travel:

Oh god, I (missing the ability to travel)...there's no future for the Traveller, the only way you will be able to travel in years to come is like this yard I've got and my brother's yard and go to my nephew's yard, that's the only way you'll be able to travel.

Whereas Mary, a younger Irish Traveller, spoke extensively about missing travelling and the sense of freedom it brings as well as her sadness of not being able to travel which has influenced her decision to want to live in a house *“I do (miss travelling) I think it's lovely when you're out in a big green field and the kids can run up and down, I wouldn't want to live in a house if I could travel”*.

This ability to be free to roam has been reduced by recent legalisation (Okely 2011) which makes it difficult for Gypsies and Travellers to pitch their wagons on the side of a road. In addition, a reduction in the number of authorised council sites (Okely

2011) and the encouraging of Gypsies and Travellers to purchase their own land on which to live, has also reduced the ability for them to maintain a nomadic lifestyle. For example Issy, a Romany Gypsy, identified, “*when you are on an authority site you are only allowed away so many weeks of the year otherwise you lose your pitch, so you end up homeless*”.

The settled community view that the provision of Gypsy/Traveller council sites addresses the problem of Gypsy/Traveller housing (Okely 2011). However, hereby lays the second experience of vulnerability identified, which related to the type of places where Gypsies and Travellers are constrained to live within. Some of the participants identified that the physical environment in which these sites are located is often of a poor quality, which is at odds with the close embodiment that they have with the natural earth. Mary spoke in depth about her experience of living within a council maintained site which is located next door to a commercial recycling plant where lorries recycle building material, as well as household items such as fridges, televisions etc. Mary (Irish Traveller) felt that the quality of the site was poor and argued it would not be deemed suitable for settled housing:

*Sometimes Travellers have to stay in places that are really bad places and you think why would they let people stay on there. Even like where we are, it's a lovely site but all around us is rubbish tips, like you wouldn't get houses in the middle of all that it's like Travellers you put them on top of the dirt they don't really care where they are and all around us there's lots of dust and it ain't the nicest of things coming down on top of you. My sister lives in ***** site it's like a bomb, it's like it's falling apart and there is much rubbish and everything.*

The participants who had experienced living on a council maintained site expressed that the sites lack physical space which impacted on them feeling enclosed and claustrophobic. This often led to difficulties with other Travellers on the site, as there was no sense of privacy which they found difficult to manage. As previously mentioned a sense of space and freedom is important to Gypsies and Travellers and as such the current provision of sites do not really address these needs for the community, as a sense of space is very important to them:

Every site you go on there's nothing but trouble, there's always arguments cos you're close together. You're like cattle in pens, big and small pitches you're on top of one another. Travellers are meant

to have space that's why you look out here it's all space, you're not closed in but you go to any site and you're like in pens. You have no privacy. You're living in a caravan and 12 meters away there's another caravan and the windows are looking in and you've got to have the blinds closed all the time. That's not the way to live, you can't live like that. But that's what the government have chosen for us to do. We got to live like that – Jimmy (Irish Traveller).

I wouldn't live in a plot there if it was come to me this minute I wouldn't have one because you're like on top of each other. It's all she said this, he did that, I think it's nice to have a caravan and you come and visit I don't want to be all on top of each other I would much rather be out on my own - Mary (Irish Traveller).

As well as a lack of space which reduced their ability to feel physically free, Mary also identified that this freedom was further hampered by the management of the sites. Where Mary lived there was CCTV cameras which added to her feeling of being watched and therefore controlled. What was also worrying for her was that at times other cameras appeared and she did not know to whom they belonged and this impacted on her ability to feel comfortable in her own home:

Two sites I spoke about you've got cameras, you wouldn't get a camera outside the front of the house so why do Travellers. It's like you go home tonight and they put a camera outside your house that cameras watching every move we make and it ain't nice.

Last year we noticed that someone put a camera up illegally and it was like at the top end on the side of a stick with like the camera facing down with wires coming down the minute we talk council about it in a couple of days later it was taken down but I don't know if that was something to do with the council, I don't know who it was. But obviously then we couldn't relax because we didn't know who put the camera up.

5.2.2 Fear of the future and declining physical health

The next aspect of vulnerability identified from the older Gypsies and Travellers related to a fear of the future and declining physical health. It is known that Gypsies and Travellers have a poorer health status compared to their age, sex matched counterparts in the settled community, and were significantly more likely to have a long-term illness, health problems or disability (Parry et al. 2007). Two of the male participants in particular, identified ongoing health issues which had resulted in previous stays in hospital. However for Tommy (Irish Traveller) this was a difficult experience due to a feeling of being frightened of both the environment as well as a fear of contracting a nosocomial infection:

I don't have the best of health, I'm asthmatic and as you get older you have more problems. I avoid going, I'll only go if I've desperately got to go/don't like going, don't like being involved... hate hospitals. I find them quite frightening places, people are ill and dying... I want to get out as fast as I can really – Tommy (Showman).

Tommy spoke about trying to escape from the hospital setting when he was very unwell and then discharging himself against medical advice in order to get home. He told me how he avoids accessing healthcare, preferring natural remedies such as nettle tea and this has resulted in him becoming very unwell in the past. His mother informed me that she once found him in a semi-conscious state which resulted in him being admitted to the Intensive Care unit with pneumonia, the same episode in which he spoke about above. Where Tommy lives it is very isolated and very peaceful, you just hear the birds singing. He also has limited social contact unless he seeks social engagement and as such it is easy to see why a noisy and busy enclosed space may be frightening for him.

Accessing healthcare is also more problematic if you are nomadic and has resulted in some Gypsies/Travellers becoming more creative in order to access healthcare such as attendance at emergency departments for primary healthcare. However this also creates problems in that it is not seen by healthcare professionals as an appropriate action:

But nearly everyone you go to they say to put down for temporary and that can take maybe a week or so. But in that time, that week while you're waiting to see the doctor you're pulled out. Do you know it's very, very hard to go into the surgery and see a doctor. So basically what we do is we just go to the A & E, the emergency hospitals and the doctor will see you. But they will only see you once - you can't keep going back. You've got to get a GP and if you're on the road it's near impossible – Jimmy (Irish Traveller).

This difficulty in accessing healthcare coupled with poor physical health has also contributed to some Gypsies and Travellers becoming more settled in order to access the ongoing healthcare support they require. Jimmy's granddaughter was born with significant physical health issues which required them to become settled. Initially, they even tried living within housing to meet her needs but found this difficult which prompted him to purchase land on which they could live, *"I have tried*

to live in a house. I tried living in a house when my granddaughter was born cos the doctor said that she couldn't live in a caravan cos there was a lot of machines that she had to be on that time. We tried it for 18 months. It was just like - well it was horrible”.

For Issy, her vulnerability was linked to a fear of becoming dependent in the future and losing her independence. She was especially worried about the possibility that she could end up requiring long-term institutionalised care either a hospital or a care home which would consequently separate her from the Gypsy/Travelling community:

My future I fear. I never thought about it before but I've had plenty of time to think about it that I don't want to live to the age where I'd be a burden on the boys. They would have to put me into care. I've got a fear of going into care. I would rather die than go into care.

I think losing your identity would be a lot to do with it. Because I think Gypsies, the Romany community never, when I say never I believe that there is several in now what I've heard in the last couple of years, which I would never have heard of before, but it is families like me that has got no daughters that end up being put into care. Part of our culture is that when you are old you are took back within the community and you are looked after by your immediate family with help from others, which we do.

5.2.3 Being an outsider

Another experience of vulnerability that emerged from the data was linked to a feeling of vulnerability related to being an outsider; this experience of vulnerability contained two similar but distinct variations.

5.2.3.1 Insider identity

The first related to an insider identity coming from within their own culture, whereas the second related to an outsider identity, that is how the participants were perceived by others outside the Gypsy /Travelling community and within wider society. Firstly, the insider identity variant linked strongly with a notion of self-segregation, of keeping to one's own *“that's just the way we feel, that people don't trust us, and therefore we stick to our own,”* said Christina, a Romany Gypsy. Many of the participants would refer to *“my people”* or *“you country folk”* or *“Gorgis”*. Issy, a Romany Gypsy, felt that the urge to stay within one's own was something she had

been brought up with, as a child she was warned against the settled community, that they could not be trusted, she told me *“it is the sort of thing that over the generations, and I mean there’s 600 years of generations of being segregated, poked at, made to stand out. You just cling to your own environment; you cling to your own family”*.

This self-segregation was particularly important to Mary (Irish Traveller), especially with regards to secondary school education as some of the topics presented in school were not deemed appropriate to her as a Traveller girl; this was especially applicable with sex and drug awareness sessions. Therefore preferences with regards to education were home schooling or if they were attending school, then a one-to-one tutor:

In the bigger school they had me a one-to-one tutor. I had to go to the school but I was separate from everybody else. Me mam didn't want us mixing with other kids, because you get a lot of other kids talking about things that we were not allowed to know about. You see in the travelling community you don't get kids talking about things like drugs or talking about sleeping with people...so like in the travelling community you're not allowed to talk about things like that but outside the community you do hear some people talking about things like that and we wouldn't be allowed to sit and listen – Mary (Irish Traveller).

These actions with regards to self-segregation may have been a mechanism for coping with their vulnerability related to the outsider identity, as choosing to stay within their own community and not integrating with the settled community helped them to feel more wanted, loved and confident. Yet conversely, it also perpetuates their outsider status for it does little to challenge or ameliorate some of the difficulties they encounter with the settled community. In addition, it does not help them to feel part of society which they view they do not belong to as it's the “Gorgi” non-Gypsy way of life, and this can increase their sense of isolation and dislocation within society and therefore contribute to their ongoing experience of feeling vulnerable related to being an outsider. Tommy, a Showman, sums this up by reflecting, *“Coming from the travelling community. I don't feel connected to the settled community at all”*.

Indeed, through their managing their vulnerability linked to being an outsider and the variant of the insider identity furthers the division between the two communities perpetuating a lack of trust on both sides. This can occur on a superficial level, for example Tommy (Showman) described how he is ignored by members of the community in which he lives, and his response to it, in that it almost becomes a game in which he deliberately says hello knowing they will not acknowledge him back, *“You’ve just got to get stronger over it ‘cos they don’t care. I still nods at them and I salute them and still acknowledge them and they just blanks me, I start to amuse myself by it”*. However this distrust is also integrated at a much deeper level within the Gypsy/Travelling community in which they feel persecuted by the settled community.

Issy (Romany) spoke of her childhood and how she was brought up to distrust both the police, thinking they would take her away from her family but also distrusting the settled community, which were also not to be trusted, *“We also had a fear of the law, a very deep fear of any police officers or any people like that, because it has been inbred in us to fear the law and not to trust anyone from the local community”*.

Tommy (Showman) referred to a “war” between the travelling and settled community, clearly articulating a perception that the settled community don’t like Travellers and the Travellers don’t like the settled community. He also expressed a view that the Gypsies/Travellers are persecuted both historically and currently within society. This was also felt by Jimmy, an Irish Traveller; however from Jimmy’s experience you see a sense of resilience that has been developed in response to his treatment from the settled community:

They don’t like the settled community and the settled community don’t like the Travellers. There’s a lot of Travellers they’re sick to death of the way they’ve been treated so they’ve called an all-out war against the settled people – Tommy (Showman).

Even though they were bullying me, I fight back and I fight harder even though I’d lose. Every time I got hit I would hit back and I’d fight and I’d try and fight harder. That’s the way with Travellers. If they’re put down they’ll bounce right back up. We are proud people, very proud. Proud of who we are, proud of where we come from. No matter what the outside world says, no matter what they say they will never be as good as us – Jimmy (Irish Traveller).

5.2.3.2 Perception of others outside the Gypsy /Travelling community

The second variant linked to the feeling of vulnerability related to being an outsider, was the outsider identity; how the participants were perceived by others outside the Gypsy/Travelling community and within wider society. The participants identified experiences they had had in which they felt discriminated against due to their Gypsy /Traveller status. This manifested at different levels from name-calling to physical threats and was experienced across the lifespan. Indeed for the majority of the participants the first time they experienced feeling vulnerable was when they started school as this was the first time they were largely separate from their own community and significantly exposed to the settled community. For Jimmy (Irish Traveller) it was the first time he realised he was different and not liked, *“They put me into school and that was when people first started calling me a Gypsy, smelly and stuff. And I couldn’t understand it. I didn’t know what a Gypsy was. I really realised that we weren’t liked. That we were completely different - different person to what country people were”*.

Some of the participants were older (70 plus) and therefore their experiences of discrimination at school occurred many years ago and were more physical from both staff and children. Issy remembered how the teacher would be part of the discrimination and segregation she experienced, *“this teacher would encourage the children to beat us and spit at us and kick and call us names”*. Whilst Issy’s experience was many years ago, other younger participants also highlighted their first real experience of feeling vulnerable was during their school years. Christina (Romany in her thirties) felt that because she was a Gypsy then the staff’s expectations of her educational attainment were low, even though she was academically strong and has subsequently completed an Advanced Diploma in Nursing and has registered as a nurse:

As soon as they found out I was a Traveller, they didn’t want to know. I spent my school life living as a Gypsy, unwanted in school and wasting my school years really being the Gypsy everybody expected me to be: not bothering in class and everything because that was what was expected of me.

The youngest participant Mary, an Irish Traveller in her early 20’s, told me how she felt that the discrimination of Gypsy/Traveller children was still apparent at school today and spoke of her brother and his experiences at school. She felt that he was

treated differently to other children in the school and was always the first to blame in any scenario because he was a Traveller:

One lady inside the school put me brothers to one side on days off and said why are you not coming here, what's going on at home, is your mum and dad arguing and I don't know is that lady doin it to every of the person at the school or why is it just my two brothers - Mary (Irish Traveller).

These feelings of being discriminated continued throughout the participants' lives as many expressed that they felt the settled community treated Gypsies and Travellers different. Issy (Romany) expresses this more eloquently than me saying, "*Because I don't like bricks and mortar. They bear down on me. They cut me off. They segregate me*". This was perceived by the participants to occur at both a national as well as a local level. Reasons for this discrimination appeared to be the perceived negative discourse of Gypsies and Travellers. Tommy, a Showman, expressed that Gypsies and Travellers are perceived as thieves recalling an interaction with a farmer who said "*I've caught you. I've had enough of your sort. Bloody robbing me*". For Paddy (Irish Traveller) there was frustration that people assumed that he did not pay tax "*and the people keep saying, why are you not paying taxes, well 90% of them are paying taxes. Because now you can't work without being registered, you got to be taxed registered. And this is what a lot of people don't understand*". Issy's feeling of being discriminated against due to her Gypsy status was further compounded by the treatment of Gypsies and Travellers in planning applications. Issy spoke passionately of her role in supporting "*her people*" in applying for planning permission. Issy felt very frustrated that "*when you (Gypsies) submit planning applications 85 of them get turned down at committee stage, automatically because it is a Gypsy application*".

Many of the Gypsies and Travellers involved in this research expressed a wish that they were not all stereotyped in such a manner, identifying that whilst there are good and bad in the Gypsy/Travelling community, there are also good and bad in the settled community and expressed a wish to be judged on their own merits rather than a stereotypical view:

I feel that's what 99% of the population see, that we are bad people and that we'll never get anywhere in life and that we just do everything wrong. You know, if they just got to know Travellers

before they put up that brick wall, they'd actually see that we are not a bad bunch of people. And we don't go round stealing everything and we don't go round hurting people. Actually most of us are quite the opposite – Christina (Romany Gypsy).

There is good and bad in Travellers, we are all the same, there's good and bad in the outside world as well – Jimmy (Irish Traveller).

People need to treat us differently, we are all classed as one people you don't class everybody the same – Mary (Irish Traveller).

What was interesting was this expressed wish to be seen as individuals and not a homogenised group, yet this discourse of Gypsy/Travellers is perpetuated especially as the community is a closed community and chooses to stay within its own kind. Therefore a lack of integration between the Gypsy and settled community can only further perpetuate stereotypical, homogenised views.

This outsider status, and the feeling of vulnerability it created, extended beyond school and the working environment. The participants were able to identify actual events and times in which they were discriminated against: Mary, an Irish Traveller, was thrown out of a pub because they said no “*Gypsies and Travellers were allowed*”; Jimmy (Irish Traveller) had 12 air rifle pellets shot into his post box the weekend his family moved onto land they owned and Issy (Romany Gypsy) was offered £30,000 to leave the village because she was a Gypsy. Gypsies and Travellers are recognised as a distinct ethnic minority and as such are protected under Race legislation; however it does not appear as though the Gypsies and Travellers which participated in the research felt that this afforded them any protection. Indeed Mary (Irish Traveller) expressed that the settled community “*pick one Traveller and treat them all the same, but like black people you can't treat one for what everyone else is like. You can't treat every Traveller the same*”. However, this appears the opposite to what the participants' experience:

When we first came here, the meeting up here, there must have been 150 people who went to the meeting were against us they were 100% against us – Jimmy (Irish Traveller).

People on the parishes they wouldn't let you feel like you belong to the community - Tommy (Showman).

These feelings of being vulnerable link to an outsider identity within society, perpetuating a feeling in which Gypsies and Travellers feel a lack of belonging within society which they perceive to belong to the Gorgi (non-Gypsy) world. This in turn leads Gypsies and Travellers to continue to self-segregate as a mechanising of coping with the feelings of hostility from the settled community, in order to retain a sense of belonging, of being wanted which is important for one's psychological well-being. This is evident when you read Jimmy's and Christina's experiences in which both of them have internalised the feelings of being unwanted. For Christina at 5 she did understand what she had done wrong, whereas for Jimmy (an adult) felt shame and then anger for people making him feel that way. This sense of not belonging could continue to widen the rift between the settled and the Gypsy /Travelling community, and perpetuate the lack of understanding of the two over each other:

Well, I never felt vulnerable really until I started school, going into this strange world with these strange people. It is hard enough for any child I think. But as soon as the other kids sort of realised that I was a Romany, they thought completely different of me. They didn't want to be the child to play with the Gypsy kid. You know. And obviously when you are kind of five you just kind of think: "Oh." And you do feel really wounded and what have I done wrong – Christina (Romany Gypsy).

...we feel vulnerable when we're in a public place and people are following you around and asking you to leave. Things like that I've got high blood pressure as it is and when you go in a place like that and you walk into a pub, it goes quiet. You know well that these people know that you are a Traveller or someone knows you're out of the community and wish we weren't Travellers. The pub will just go quiet and 4-5 minutes later they'll start chatting again and going back to normal. But you can see their eyes are on you the whole time. Your face will get red with shame. Why should I be ashamed? I'm walking in and spending the same money as these people and yet get treated completely differently – Jimmy (Irish Traveller).

During the process of data collection, the media was showing on television "My Big, Fat Gypsy Wedding" and "My Big Fat Gypsy Christmas", two programmes which followed Irish Travellers on their wedding days and over the Christmas period, showing an insight into this largely hidden community. However there appeared to be a mixture of views regarding the programme, in that some of the Romany Gypsies felt it provided a homogenised view of Gypsies/Traveller by presenting just one type of Traveller (Irish Traveller) which they felt did not reflect their individual cultural values. Whereas, the Irish Travellers that participated in the research also

felt the programme had misrepresented their community choosing to focus upon a highly sexualised nature which they felt misrepresented them. Jimmy highlighted *“To me they were more focussing on little kid’s short dresses and to me I said what are they showing that for. Why are they showing the way the girl dances? You go into any nightclub and you’ll see them all dancing similar. It was more or less putting the young girls down as badly behaved where it couldn’t be further from the truth”*; whereas Mary felt *“A big fat Gypsy wedding is wrong; it’s like putting the little kids in spray tans and a lot of it we don’t agree with but that’s different Travellers but outsiders watching that are going to treat all Travellers like that”*. Both Jimmy and Mary felt that the programme misrepresented their community, even though both were actually part of one of the shows. They felt that the shows presented to the settled community a one-sided view of some individual Gypsies and Travellers, that it did not represent all Gypsies and Travellers and were concerned that the settled community would take this one-sided homogenised view of them.

However, up until that programme Gypsies and Travellers have largely been invisible to the settled community, and are reluctant to open themselves out, preferring to remain hidden to non-Gypsies due to a fear of being discriminated against. Indeed, during the process of the research the researcher was surprised at how hidden the community are, especially when they live on their own land, as the majority of the sites are not visible from the road. Something which she found out during the interviewing process is a stipulation of the planning process, almost as if the settled community wants them to remain hidden from view and therefore invisible in society. This feeling of the settled community wanting Gypsies/Travellers to remain hidden was something which Jimmy (Irish Traveller) expressed when his granddaughter was born on 00.02 New Year’s Day, along with 5 babies in the settled community. Whereas the 5 babies from the settled community had their pictures presented in the local newspaper his granddaughters was absent. Despite this invisibility some of the Irish Travellers participants felt that they were very visibly recognisable as Travellers, Mary said *“People automatically assume that’s it, you’re a Traveller, but I don’t know what is it, is it tattooed across us or something”*. This identification of Traveller status was probably due to their accent which was very strong Irish accents even though they never have actually lived in Ireland. Mary felt that this visibility of their status led to them being discriminated against.

5.2.4 Vulnerability connected to the ambiguities of their historical, cultural and geographical identity

The last vulnerability that emerged from the data related to vulnerability connected to the ambiguities of their historical, cultural and geographical identity. For each of the participants their sense of having a Gypsy/Traveller identity was very strong even though they lived in a variety of different settings (house, council maintained site; own land with planning permission and own land without planning permission). The Irish Travellers that I spoke to were all born in England and had never lived in Ireland but still ascribed themselves to be Irish Travellers, denoting a strong cultural identity. Jimmy said *“So, just because I’m an Irish Traveller. I was born in the UK though. My wife was born in the UK. All my kids and grandkids were born in the UK. I wouldn’t say any of my kids have been in Ireland in all their life for more than 24 hours”*.

For Christina, her cultural identity as Romany was not challenged by where she was living. She was brought up in a trailer on a council maintained site and spent some time during her younger years in a house before they returned to the council maintained site. What was interesting for her was that whilst her perception of her cultural identity never changed, it did affect some in the settled community. She recounted an experience in school when she had recently moved into a house and the perception from others that she was no longer a Gypsy:

We moved into a house I was probably coming up to my GCSEs and it was really weird because one of the posh girls actually said to me: “Oh, now you are not a Gypsy anymore, do you fancy coming into town with me.” And I said: “No, I am still the Gypsy I always was.” And it is amazing how they did see that if I did live in a house I wasn’t a Gypsy. It was just madness.

Often when the participants were referring to the Gypsy/Travelling community they would use the term “my people” and there was a sense of belonging when they referred to their own community, thus sometimes choosing to self-segregate from the settled community (as mentioned earlier). There was a sense of an extended family within the Gypsy/Travelling community that went beyond any blood ties. Christina summarises this:

I never locked my door. I never ever felt frightened or vulnerable in my own community. I've got an awful lot, I feel, that most non-Travellers don't have. The bonding...

Even though this sense of belonging and cultural identity was strong in the participants spoken to, there was also a sense that their Gypsy/Traveller ways are being eroded due to many reasons. One of the reasons was a sense of their traditional ways being diluted due to influence by the settled community which may be due to marriages between Gypsies/Travellers and the settled community. Indeed two of the three women that participated in the study had married outside of the Gypsy community, and perhaps this influenced why they were more receptive to being involved in the research. However this has resulted in their children having a mixture of Gypsy/Traveller and settled cultural identity and a sense of living within two worlds, which at times could clash. Issy felt that her children only have half of the Romany values as their father was a Gorgi *"I've got two sons that are only half Romany, so therefore they haven't got the full values of the Romany cultures what I have. It is weakened. They've married Gorgis. So it's weakened that bond of keeping a traditional way of life"*.

Even within the families that had married their own kind there is a shift in that the traditional values are changing and younger generations of Gypsies and Travellers are being more influenced by a Gorgi way of life. Jimmy, an older Irish Traveller, felt that money was becoming much more important to the younger generation, highlighting:

And Travellers have changed, completely changed. They're like the rest of the world, money is the god. Even my own... I keep telling them money isn't everything, you only need so much, a man can have it but he can't bring it to the grave with him.

Maybe the increased focus upon money is not unusual especially with regards to the poor fiscal climate. Gypsies and Travellers are not immune to this, and indeed many of the participants expressed concerns regarding the traditional way of life of the Gypsy/Traveller are no longer viable because of the changing work patterns. Tommy (Showman) breeds and trains horses, however he feels that *"the days of the horse are gone"* and this is influenced by local bye-laws, for example, not being able

to run a horse across the village green, which means the buyer is less likely to purchase the horse as they cannot see it run. He also felt that the public's perception of a horse as a working animal has also changed which makes it difficult to have a working horse. Other ways in which Gypsies would traditionally work was on the land but this too is reduced due to the increased machinery used in farming and the inability to travel where the work is which Gypsies and Travellers would have traditionally done. Both Christina (Romany) and Jimmy (Irish Traveller) felt work for Gypsies is more difficult, perhaps influenced by stereotypical views the settled community have regarding Gypsies and Travellers:

Because you know the Traveller way of earning a living and everything is certainly dying out – Christina (Romany Gypsy)

There is no work – Jimmy (Irish Traveller).

Because of this shift in the cultural identity some of the participants expressed a feeling of living within two worlds, the settled community and within their traditional Gypsy/Traveller community and sometimes these two worlds could collide causing conflict. This was especially difficult for Christina (Romany Gypsy), Christina went to catering college after school and then later trained to be a nurse and holds a senior position in the environment in which she works. For Christina, this sense of living within two worlds was extremely difficult towards the end of her father's life when the nurse that she was wanted to direct the care he was receiving in hospital but her position as a woman in a Romany Gypsy culture was not to direct but be led by the males in her family, (who did not have her knowledge regarding health or healthcare). Christina spoke of feeling torn during this time, a time when she openly admits she felt the most vulnerable she had every felt in her life:

Some of them used to take the mick (about her going to college), saying you know you want to be a Gorgi...So the roles almost reversed who was having a dig. Do you know what I mean? And they saw that I wanted to leave my family and Romany life behind and become a Gorgi.

I feel that my brothers especially more than my sister kind of play it down an awful lot the way I live my life and that I'm a nurse and everything just because it is easier than saying that my sister went off to university and I'm very proud of her and she is a qualified nurse. They would just play it down: "Oh, she works in an old people's home." Because they would almost get the mickey taken out of them if they gave them the full story.

When my dad went into hospital that I felt the most vulnerable in my life really and the most torn with what I know as a nurse and what I should do as a Traveller girl. The two just don't, they just don't meet in the middle and it does cause hard work for me.

Many of the participants expressed that they felt that the Gypsy/Traveller way of life is being eradicated by the settled community. Tommy (Showman), Issy (Romany) and Jimmy (Irish Traveller) expressed that Gypsies and Travellers are being forced to settle into housing and are losing their nomadic ways. They expressed concerns regarding the future of Gypsy and Traveller cultural identity, feeling that it is being eroded:

Most Travellers have settled down one way or another now – Tommy (Showman).

Because all the government now is trying to do is to stop planning so that they can put us in housing and hopefully we will lose our identity and behave and be one of them eventually. That is their aim. ..there is a sinister element here that we are going to go through another ethnic cleansing – Issy (Romany Gypsy).

You take it from me, within another 20 years, and in time that's not that long, and you won't see a Traveller on the road it, it's gone. In this day and age now the way that's going on with Travellers and that, I can only see one thing happening, they want to wipe us out...that's what I'm saying You might say that its going a bit too far, but I'm telling you honestly and a lot, lot of people of my culture are thinking the same way – Jimmy (Irish Traveller).

The words that the participants used to vocalise this feeling were incredibly strong, using phrases such as “ethnic cleansing”, “being wiped out”, “being erased”, “being getting rid of”, and a sense that the Gypsy/Travellers' ways are doomed so in the future there would not be any Gypsies or Travellers left. Both Christina (Romany) and Mary (Irish Traveller) both expressed sadness and concern that their children and their children's children would lose their identity as Gypsies and Travellers and felt that it should be preserved:

In years to come there will be no Travellers, no offence but people like outsiders are just going to try to erase Travellers to get rid of them like we were never there – Mary (Irish Traveller).

Because you know the Traveller way is certainly dying out – Christina (Romany Gypsy).

This chapter has presented some of the rich descriptive accounts of the lived experience of vulnerability that the participants expressed when asked:

“Can you talk to me about your life as a Gypsy/Traveller and describe all the times the word vulnerability applied to your life, times in which you have felt vulnerable”.

It was evident that the participants had experienced feeling vulnerable due to many different reasons which were presented in this chapter as different facets of vulnerability. They experienced feeling vulnerable due to their culture as Gypsies and Travellers by a lack of actual or physical travelling experience as well as the ambiguities of their historical, geographical and cultural identity. Vulnerability was also linked to interactions with others in society and feeling like an outsider which led to a degree of self-segregation. Lastly, vulnerability was linked to age and health and a fear of the future. The next chapter identifies which aspect of vulnerability was chosen as the focus for the breadth study and the research methods chosen to explore it.

Chapter 6 Research Method of Phase 2 (Depth Phase)

6.1 Introduction

This second methods chapter commences by articulating the chosen facet of vulnerability that will be the focus for Phase 2 of the study. It then presents a rationale for the chosen method of descriptive phenomenology as the appropriate method for the depth phase of the study. It progresses by presenting how maximum sampling variation (Langdrige 2007) occurred through the recruitment strategy in Phase 2 and presents how concrete life-world experiences were captured. This phase led to some difficulties, notably with regards to methodological and ethical challenges and both of these are explored here. The chapter concludes by presenting a detailed overview of the process of analysis used (Giorgi 2009).

6.2 Focus of Phase 2

The analysis of the data in Phase 1 provided rich and evocative descriptions about the individuals' experiences of feeling vulnerable related to travelling, health and fear of the future, being an outsider and being part of a cultural group whose identity was under threat (see chapter 5, findings Phase 1). Upon reviewing these different phenomena, one in particular struck the researcher as something she wished to explore further and this was the link between the perceived enforced cultural change and the impact upon the individual's identity. The findings of Phase 1 identified that participants spoke about a disjunction between their inner values and identity as a Gypsy/Traveller and a sense of feeling as an outsider and not feeling free which impacted upon their feeling vulnerable. It seemed as if there was a particular kind of vulnerability prevalent in Gypsies and Travellers which related to their experience of being part of a cultural group with threatened cultural identity and heritage. It was this phenomenon that was explored further in stage 2.

6.3 Descriptive Phenomenology

Descriptive phenomenology was the methodological approach chosen for the depth aspect of the study as there was a desire to hear and privilege the descriptive accounts from individuals within the Gypsy/Travelling community. The purpose of descriptive phenomenology is to describe a phenomenon and its meanings without interpretation, explanation or construction. It is therefore important that the

researcher does not ascribe meanings that are not there; instead present the richness and complexity of what is presented to them by revealing the essential general meaning structures of the phenomenon (Finlay 2009). In doing so researchers can “find insights that apply more generally beyond the case that was studied in order to emphasise what we may have in common as human beings” (Todres and Holloway 2010; p178). Gypsy/Travellers are often marginalised within society through the process of othering which prioritises the differentness between Gypsy/Travellers and the settled community, therefore an approach which focussed upon our shared humanness was deemed positive.

Amedeo Giorgi is recognised as evolving the Husserlian philosophy of phenomenology into a scientific method of undertaking phenomenological research. Whilst specifically developed for psychological research, it is now being used across the social sciences disciplines and is sometimes referred to as the Duquesne approach. This approach has many benefits, most notably is the provision of a clear structure and systematic approach for the analysis (Giorgi 2009) which was attractive to the researcher who was new to phenomenology.

6.4 Interview Schedule

Again Phase 2 incorporated an experience near question which is fundamental to phenomenological research, as the goal was to have as many concrete descriptions of their experiences of vulnerability related to their culture of Gypsies/Travellers. This evolved from reviewing the findings of Phase 1 and in particular to explore the aspect of vulnerability related to their perceived threatened identity. The experience near question used was:

“I am interested in a certain kind of vulnerability that is linked to being part of a group whose cultural ways are being threatened. I would really like to understand this further. Tell me about stories/times in your life when your Gypsy/Traveller ways felt somehow challenged or threatened or not easy and what this meant to you”.

Once again interviews were held in the participants’ own homes, as experience from Phase 1 clearly demonstrated it facilitated the individuals sharing their stories with me. Whilst the interviews were planned to be single, one-to-one interviews, which is more common in phenomenological research, the reality was that the majority of the

interviews were group interviews. This occurred because of the nature of the community, coming together in groups, therefore during the one-to-one interviews members of the participant's family were sometimes present and would also participate or would drop by unplanned and stay and participate in the interview. Whilst this made the interview schedule more challenging it designated the level of trust the community had in me as a researcher and how comfortable they felt with me to join and share their experiences. Whilst group phenomenological interviews are still the minority, there is a growing body of evidence which identify group interviews can occur (Wu et al. 2010; Lee et al. 2012). Bradbury-Jones et al. (2009) identify that phenomenologically-orientated interviews can occur in a group setting as it allows the participants to hear each other's stories and then add their own perspective, leading to a richer understanding of the phenomenon under study. Yet it is recognised that in doing so it may inhibit the breadth of experiences presented. In the context of this study, the purpose of Phase 2 was to offer the depth of understanding of vulnerability associated with being part of a group whose cultural ways are being threatened and therefore group interviews worked well.

6.5 Sample

It was initially hoped that participants from Phase 1 would be re-interviewed in Phase 2. However, due to the length of time it took to recruit participants to Phase 1; by the time it came to re-interviewing participants (over a year later) many of the participants had moved on, or had left to go travelling. Therefore, only one participant interviewed in Phase 1 was re-interviewed in Phase 2 (Jimmy) and further participants were recruited to the research. Within this phase a variety of differing Gypsies and Travellers were included (Table 11); the youngest participant being 17 and the oldest 78, including both men (n=2) and women (n=11); Irish Travellers (n=6), Romany Gypsies (n=4) and English Gypsy/Travellers (n=3). Whilst the majority of the participants were married (n=7), the sample also included individuals who were divorced (n=2), widowed (n=2), single (n=1) and cohabiting (n=1). Of those who were in relationships, predominately these were within the Gypsy/Traveller community although three of the participants in the study were either cohabiting or married to someone outside of the Gypsy/Traveller community. The majority of the participants within Phase 2 were living on a council maintained site (n=11), however, they do not all live within the same site, but across three separate council maintained sites and two participants live on land they own. All but three of the participants have children (n=10). Brief biographical details of the

participants are presented in table 11. It is important to note again that fictional pseudonyms have been applied to each participant in order to respect confidentiality whilst also recognising them as individual human beings.

Table 11 Biographical details of participants Phase 2

Brief Biographical details of the participants

Jimmy - 59 year old Irish Traveller. He lives with his wife (Dena), daughter (and her family) and two of his sons (with their families) on land that he owns. They have lived on the site since they purchased the land four years ago; they have only recently been awarded permanent permission to live on the site.

Dena - Irish Traveller, who lives with her husband Jimmy, see above.

Johnny - 65 year old Romany Gypsy. Johnny has spent the majority of his life on the road travelling, but due to ill health he can no longer travel and now lives with his wife (non-Gypsy) and 3 dogs on a council maintained site.

Cora - 65 year old widowed English Gypsy (husband was an Irish Traveller). Two of her daughters and their children also live on the same site as her. Cora lives with her disabled daughter and her dog.

Nadya - 20 year old married Irish Traveller; her husband is an English Traveller and they live with their small child (less than a year old) on a council maintained site. She has previously lived in housing as well as on sites.

Layla - 21 year old Irish Traveller. She is divorced, having been previously married to a countryman (non-Traveller) who was violent towards her. She lives with her parents on a council maintained site. She is currently at college undertaking a beauty therapy course but had previously spent a year undertaking her nurse training, and she works part time as a healthcare assistant at a local hospital.

Girlie - 17 year old Irish Traveller who lives on a council maintained site, with her mum and dad and sisters. Has extended family on site – got engaged recently.

Daisy - 78 year old English Traveller who has lived on a council maintained site for the last 20 years. She was widowed two years ago and is waiting to move into a flat. Daisy has 2 daughters who are married to Travellers with young children, and they live in houses locally to her. The site is very enclosed, located behind some buildings; therefore Daisy looks out on to brick walls.

Rawnie - 23 year old Romany Gypsy who is married to a Gypsy and has a young baby (only months old). She has travelled extensively throughout her life, and only recently become more settled on a council maintained site since she married. Whilst she has family who live locally she is unable to see them often because she cannot drive.

Shauna - 36 year old English Traveller who lives with her partner (non-Gypsy). Shauna's mother lives next door to them on the council maintained site.

Orla - 35 year old Romany Gypsy who lives with her husband and 6 children on a council maintained site.

Lizzie - Irish Traveller who is married to a non-Gypsy (who was brought up by Gypsies since an early age). She lives on a council maintained site, with her extended family.

Alanna - 30 year old Romany Gypsy. She lives on a council maintained site which has been earmarked for redevelopment. Alanna is divorced and lives with her young son (toddler).

This re-recruitment was, on reflection, a strength as it enabled a much wider diversity of participants within the study, thus aiding maximum variation sampling (Langdrige 2007). It is important within this that whilst participants have the shared experience of vulnerability, they vary on as many demographic characteristics as possible such as gender, age, type of Gypsy/Traveller, and differing lives as Gypsies and Travellers. This enables the researcher (during the analysis) to identify the aspects of the experience that are invariant across perception (the essence of the phenomenon) and those that vary across perceptions (psychologically sensitive variations) (Langdrige 2007).

Due to the difficulties experienced in recruitment in Phase 1 a decision was made to access the community through a council site manager and this was really key in accessing the community. Brown and Scullion (2009) concur that site managers are often an excellent first point of contact. This made recruitment to Phase 2 much easier as the site manager utilised had an excellent relationship with the individuals living on the site and as such they were more receptive to meeting and talking to me. Whilst the site manager made the initial introductions, he did not participate or stay in any of the interviews. In addition, the role of the researcher was made explicit and participants were reassured that what they chose to share would not be shared with the site manager. This resulted in a large number of the participants in Phase 2 living on council maintained sites and it must be recognised that differing data may have been obtained if individuals living on their own land had been recruited. However, participants lived on three differing sites and therefore their experiences of living there were different. In addition, recruiting more individuals who live on their own land or are transient is challenging; experience from Phase 1 highlighted that often an individual would not be aware there was a private Gypsy/Travellers site located in an area unless they knew it was there as they are usually hidden from public view (a stipulation of their planning application) and this makes a hidden community more hidden. Using site managers could also have potentially inhibited the experiences shared due to a fear of their thoughts being shared with the site managers. The reality did not reflect this, as individuals were open and honest regarding their feelings of living on the site.

6.6 Ethical Considerations

Similar to the ethical issues that arose in Phase 1, in Phase 2 often additional participants would stop by during the interview and a similar strategy of transparency of information was employed. Ensuring that everyone was informed of the purpose of the discussion, they were aware it was being audio-recorded and consent to participate was obtained. An additional ethical issue arose in Phase 2 with regards to Girlie. Girlie was a 17-year-old Irish Traveller who joined in with a group interview with both her mum and sisters and this was difficult as the study had not planned to interview people under eighteen due to consent issues. Whilst I did not actively recruit her to the study, I did not feel it was appropriate (in her own home) to ask her to leave the environment nor to keep silent. This led to an ethical dilemma regarding what to do with the information she shared. On one hand, her

comments could be disregarded from the study as she fell within the exclusion criteria of the study and ethical review did not include interviewing people under the age of eighteen. Yet a critique of these ethical systems could be that it can result in a reductionist approach to ethics, one that sees ethics as a product which is obtained rather than a philosophical and moral process which guides one's practice. In contrast, one could view ethics as a philosophical consideration that guides individual practice throughout the process of conducting the research. In perceiving ethics in this way disregarding Girlie's contributions could be perceived as unethical as it ignores her voice, her thoughts and thus denies her citizenship. Ultimately, I was guided by my own professional accountability as a nurse and judged that she was able to make an informed consent to participate, her mother was also present and therefore her thoughts were included in the study.

6.7 Analysis

Unlike Phase 1 the analysis of Phase 2 occurred after all of the interviews had been undertaken. This decision was based upon two factors; firstly a pragmatic decision as recruitment was much easier (as previously identified), and secondly as an embryonic phenomenologist it was important to be able to immerse myself in the analysis in order to fully develop my understanding of it. Whilst the interviews undertaken in Phase 2 were often group interviews (see 6.4) each of the participant's data was analysed individually, in order to explore their own lived accounts of vulnerability.

The data from the interviews was analysed following Giorgi's descriptive phenomenological method (Giorgi 2009). Phenomenological analysis follows a tripartite structure, described as a movement between the whole, the parts and the whole (Dahlberg et al. 2008). It is imperative that each part is understood in terms of the whole and the whole is understood in terms of its parts. This tripartite structure is best described as a spiral, moving from interviews (the original whole) to analysis (parts) to a new whole (Dahlberg et al. 2008). This was achieved by following the three step process articulated by Giorgi (2009) and Giorgi and Giorgi (2003b).

6.7.1 Giorgi's Phenomenological Method of analysis

The data was initially transcribed verbatim in order to have written transcripts to undertake the analysis. For each of the written transcripts the following steps of Giorgi's process were undertaken:

- 1) Read to gain a sense of the whole

Each of the individual transcripts was read in order to get a sense of the whole description of the individual's account. This reading for the sense of the whole did not include explicitly identifying aspects of vulnerability but rather its purpose was to enable me to enter the world of the other, to develop a sense of their individual story. This would also include re-listening to the audio recordings in order to re-immense myself in the individual's account.

- 2) Determination of the meaning units

Once I had developed a sense of the whole the next step is to identify the meanings of experience. Parts have to be established to be able to achieve a more thorough analysis (Giorgi 2009). The parts are established based on meaning discriminations and are referred to as meaning units. To achieve this, the whole transcript was re-read from the beginning and every time there was a shift in meaning a mark was noted in the written transcript. This continued until the whole raw data was broken down into meaning units which were embedded into a table for the next stage of analysis (see appendix 13). At this stage of the process I took one of the transcripts, transposed into meaning units, to one of my supervisors for clarification and discussion and she had split the same transcript into differing meaning units. Giorgi (2009; P130) notes this is an arbitrary process and recognises that different researchers may assign differing meaning units and stresses this is not important as the meaning units do not carry theoretical weight but rather are a mechanism of making the descriptions more manageable.

Integral to this was the need to focus upon the data with a phenomenological attitude, which Finlay (2011) identifies as a willingness to put aside one's perspective of seeing the phenomenon in order to see it with fresh eyes, to be open to see what we have not seen before, a process which is referred to as bracketing. Giorgi (2009) recognises that many researchers are confused with the process of

bracketing assuming that they have to forget their past knowledge. Rather it is about not letting that past knowledge influence the analysis of the present experience. This process of bracketing in theory was easier than the reality. At times during the research I had to be consciously aware not to be influenced by the findings from Phase 1 but to give myself space for new insights and new ways of seeing the phenomenon as I moved through the data analysis of phase 2 (for a more detailed reflection of this see chapter 9). In reality I had to consciously separate the two Phases and put aside what I had heard there.

3) Transformation of the participants' natural attitude expressions into phenomenologically psychologically sensitive expressions.

This step is at the heart of the phenomenological attitude (Giorgi 2009). In this step there was a return to the beginning of the description which had been sectioned into meaning units. Each meaning unit was then reviewed exploring each in turn, examining them to identify how to express the life-world description of vulnerability in more suitable ways (referred to as psychologically sensitive expressions). In order to achieve this, the process of free imaginative variation was used, dwelling with the transformed meaning unit to discover the psychological meanings being lived by the participant, revealing the nature of their vulnerability (appendix 14). Throughout this process the analysis was shared with the supervisory team in order to check the analysis. Giorgi (2009) asserts that this is a sound strategy which will ultimately strengthen the data produced.

This three step process was undertaken for each of the thirteen participants in Phase 2. At the end of this process there is a shift again from the parts (each interview analysed) towards the whole, in which there is a process of identifying the constituent structures of the phenomenon of vulnerability experienced by Gypsies and Travellers. Again the process of free imaginative variation was used to identify what were the aspects that were at the heart of the life-world descriptions of the accounts of vulnerability expressed by participants not at a level of universality but generality (see section 3.7). The purpose of this movement between the parts and the whole is to bring together the essence of the experience of vulnerability. This process was very time consuming and required me to be fully immersed into the data. At times I became too embedded with the detail and had to force myself to

take a step back to dwell with the data, to continue to use free imaginative variation as I tried to travel beyond the superficial towards the depth, identifying the essence of their experience of vulnerability. Finlay (2013; p186) identifies “the more you dwell, the more you will feel yourself engaging with the phenomenon”. I had to learn to be patient and take the time to dwell within the data.

Finlay (2009) argues that researchers need to embrace the intersubjective relationship between themselves and the participants, in her earlier work referring to this process as a dance. My role during the data analysis phase was to leave consciously behind my own perspective (both theoretical and personal) and allow myself to be brought into the lives of the participants, seeing the world from their eyes. Intersubjectivity is defined by Cornejo (2008) as the space in which we are being in the world with others. Throughout the analysis of the data I found myself experiencing this as I moved further into the individual experience. I found myself transported from the beginning of the analysis considering it from a third person perspective towards a first person perspective using ‘I’ in the articulation of the essence of the experience of vulnerability. The findings enabled the humanness of the experience of vulnerability to transcend our differing cultural backgrounds.

6.7.2 Credibility of analysis

The credibility of the analysis was ensured by firstly providing a detailed step by step approach articulating how the themes in stage 1 and essences in step 2 arose from the data. Within considering credibility in qualitative research the notion of interpretive validity often arises. This is achieved through member checking where the researcher takes back the analysis to the participants so participants can compare this analysis of the data with their experience. It was felt that it was not appropriate for this study; firstly, because the research was exploring the essence of the phenomenon of vulnerability rather than the general experiences of vulnerability which were experienced by the participants. Indeed, Giorgi (2010) argues against member checking for this very reason, identifying that the researcher is interested in the essence rather than the general meaning, highlighting that there is a difference between this raw experience and its meaning. Therefore credibility was ensured through sharing the stages of the analysis with experienced phenomenologists who were then able to critique guide and stretch the researcher into a far greater depth of analysis. External judgement was also sought by sharing the proposed

methodological approach at an international conference with methodological experts (appendix 9).

This chapter identified the methods by which the depth phase of the study was conducted. It articulated the systematic process by which data was collected and analysed using Giorgi descriptive phenomenological method (2009). Furthermore, it highlighted particular ethical challenges that arose during this phase. The next chapter presents the findings from this phase of data collection.

Chapter 7 Findings of Phase 2 (Depth Phase)

7.1 Introduction

This chapter presents the findings from the descriptive phenomenological analysis of the data from the second set of interviews which asked “*tell me about stories/times in your life when your Gypsy/Traveller ways felt somehow challenged or threatened or not easy and what this meant to you*”. The analysis of the data produced rich, powerful and evocative descriptions on the ways in which the individuals in the Gypsy/Travelling community experienced feeling vulnerable due to the ambiguities of their historical, cultural and geographical identity and these are presented here.

7.2 Constituents

In phenomenological analysis, the purpose is to identify the essence of the phenomena, its constituents and any psychologically sensitive variations (see Chapter 6). Giorgi and Giorgi (2003a) recognise that for simplicity it would be useful if one single structure could be identified for all of the data. Yet they recognise that this is unlikely to occur and caution against forcing the data to fit a singular structure. Therefore within the structure there may be multiple constituents and the general structure refers not only to these but also the relationships between them. Ultimately, Reed (1986; 102) identifies that to “describe the structure is to describe how the elements of a phenomenon function constitutively; how they interrelate to form the unity of the experience”. Different writers either present the constituents leading to the essence or the essence first then the constituents. The former resonated with me as I felt that the reader needed to be able to hear the parts before the whole, as for me, similar to Aristotle “the whole is greater than the sum of the parts”. As such within this chapter, the constituents shall be presented first and the essence of vulnerability presented last.

Within the analysis six constituents of vulnerability related to being part of a cultural group with threatened cultural identity and heritage were identified:

- Vulnerability due to feeling defined and homogenised in a particular way
- Vulnerability of feeling pressurised to conform to live a particular way
- Vulnerability of feeling split in one’s identity

- Vulnerability due to feeling a loss of one's heritage
- Vulnerability of feeling discriminated, persecuted and threatened
- Vulnerability of powerlessness

For clarity for the reader the constituents have been separated; yet the lived reality of vulnerability of the participants embodies these simultaneously. As such many aspects of these constituents interlink, however there is sufficient difference to identify them as separate. In addition, during the process of analysis it also emerged that the participants responded to the different experiences (constituents) of vulnerability in differing ways such as:

- Living inauthentically
- Complexifying one's identify
- Mourning
- Hiding and resigning
- A resisting rebellion

Whilst these responses are not constituents of vulnerability but responses to them it is important that they are identified and presented as part of the individual's lived experience of vulnerability. Where these responses occurred, they have been presented after the associated constituent. Each of the constituents will now be presented in turn.

7.2.1 Vulnerability due to feeling defined and homogenised in a particular way

Each different type of Gypsy/Traveller has a very distinct culture and value base, even though they may share a common nomadic cultural heritage. However the first constituent of vulnerability, Gypsies/Travellers felt defined and homogenised rather than their individual cultural identity being perceived. Participants expressed a desire to be viewed as an individual rather than being categorised together, seeing the uniqueness of their own particular cultural identity as English, Irish Travellers, Romany or English Gypsy. Instead they felt they are treated as a homogenous group by society which categories all Gypsies and Travellers as the same, resulting in their uniqueness becoming invisible:

In the street, they call us Gypsies but we're not Gypsies....we're Travellers – Daisy (English Traveller).

Shauna (English Traveller) feels frustrated that there is little identification of the differences between differing Gypsy/Travelling cultures, especially in the media, as they tend to be presented as a singular community making invisible the distinctive differences between them:

*“It’s like this Irish Fat Gypsy weddings. Since that’s been on, I’ve seen a change in the Traveller community again, because they’re Irish and we’re English. It’s like they’re saying that men’s got to grab the girls under 18 to be married and things. And we’ve been asked this over and over. People asked why ain’t we married and “Did **** grab you?”*

It feels to the participants that there is almost a simplistic view of their community, rather than recognising that even within the same group, for example, Irish Travellers each family may have their own particular values which may not reflect those of the wider Traveller community:

I think it’s different with different families, different Traveller families. It’s a lot different because some of them like old-fashioned ways and they stick to their ways, whereas there’s other Traveller families that are more open-minded now and they’re moving with the times. – Nadya (Irish Traveller).

An example of different values and beliefs is provided by one of the families interviewed; mum (Lizzie) and her three daughters (Nadya, Layla and Girlie) aged 20, 21 and 17 respectively. Each of the daughters have a different perspective regarding their personal beliefs and values even though they would all ascribe themselves as Irish Travellers and have shared a similar upbringing. Nadya prefers to be settled, and does not really enjoy travelling. She attends college and is training to be a beauty therapist. Previously she has undertaken one year of nursing training and works in a hospital as a healthcare assistant. She would happily live in a house. Layla, her older sister, loves to travel and would never consider living in a house. She prefers a more traditional Traveller life and stays at home to raise her son. Her hopes for her son are that he would marry a fellow Gypsy /Traveller and would travel and have a nomadic life. Girlie has recently got engaged to another Traveller and plans to be married within three months. She is due to go off travelling with her

family (Lizzie and Nadya) and knows when she marries she will have to leave her family and live with her husband's family. She also would never consider living in a house.

Within this sense of homogeneity, the participants identified that as Gypsies and Travellers they are negatively perceived and judged by the perception of the actions of the whole community rather than as individuals themselves. This feels very unfair to them and they feel they can do little to challenge these perceptions. They are frustrated their individual actions do not appear to be taken into consideration. That somehow their individuality is invisible, clouded by the negative wider societal perceptions of them as a homogenised group:

Gypsies all get classed the same ...we're getting classed all the same. And still, in the Gypsy community, there are many different Gypsies. There's the English Gypsy. There's the Irish Traveller. And then, you get like the hippies and the like...like new age and stuff that isn't from the Gypsy community – Alanna (Romany Gypsy).

It's like if one Traveller does something wrong we are all tarred with the same brush instead of just saying "Well, that one has done wrong." Like I said, if one does wrong, like I said if at a club and that one does wrong then throw them out. But don't throw me out when I have never ever done anything. I've never caused trouble. I've never been in trouble in my life. Do you know what I mean? That's what upsets me I think. – Orla (Romany Gypsy).

...you see, people takes them as Gypsies. So, a genuine Gypsy is all tarred with the same brush, you know? It's no good saying to people, "Oh, it's not us. It's so and so and so." You know, they...that wouldn't wash. You can't really say it ain't you or it's not your kind, but there you go. – Johnny (Romany Gypsy).

7.2.2 Vulnerability of feeling pressurised to conform to live a particular way

The second constituent of vulnerability identified was a vulnerability of feeling pressurised to live a particular way. Feeling pressurised to conform is reflected in the participants' feelings of a lack of control over their own lives and destiny. There is an inability to live the life that previous generations have, due to restrictions imposed upon them from wider society. Within this, there were the components of not being able to travel and secondly not being free to follow their cultural norms. An ability to be able to travel was vital to participants, many of whom spoke of loving the sense of freedom that travelling provided for them. This was not only freedom in a physical sense due to the open road and being out in the physical world, which was important to them (as was also identified in Phase 1), but there was also a

psychological feeling of being free, having the freedom to decide where and when to stop and when to move on. Psychological freedom was important to them as Gypsies and Travellers:

You know, we just like, just like in the free. We don't like to be closed in – Jimmy (Irish Traveller).

..It's a way of life; you're born to be that way, to be that way...– Dena (Irish Traveller).

You can come and go as you please...– Rawnie (Romany Gypsy)

..on the side of the road, well, you can see the cars going up and down. It was lovely. There was lovely trees...the birds...– Daisy (English Traveller).

.. I would love to be on the road, right this minute..... Sense of freedom, I suppose, really, in one sense. I don't really know how to put it, it makes you feel like different because you're doing the things that you used to years ago, you know what I mean? - Johnny (Romany Gypsy).

Therefore an inability to travel was met with a profound sadness by the majority of the participants. Cora (English Traveller) stated, “*I miss travelling I do*”, whilst Shauna (English Traveller) recognised, “*We don't do our thing our way*”. For many of the participants, due to the changing legislation, the perceived feeling of freedom they gained from travelling has now been lost and instead travelling has almost become synonymous with struggling and hardship. Jimmy (Irish Traveller) expressed how the only way that Travellers can now travel is to move from privately owned site to another privately owned site as pitching on a public place is now virtually impossible to achieve. If they do manage to pitch in a public place they are moved on by the police very quickly. For him, this is incongruent with the way in which he should live, incongruent with who he is, and as such imposes an inauthentic way of being. All he wants is to be allowed to live a Travellers' life:

And it just got harder and harder and you'd start going to places and it'll be all boulders and anyway you couldn't get on them, you know. Now today places will have you off in an hour. So, all we do now is just go from yard to yard.

Listen; please listen here, all we ask for is a Traveller's life of this government. But the government... they can't understand it...they never did understand it. All I ever wanted to do, all we ever wanted to do was travel around and mix with our own people...

Cora (English Traveller), who is no longer able to travel due to ill health, spoke extensively and with longing about her travelling days when she was younger and yet experience through her family has exposed her to how difficult travelling life is today:

I miss travelling I do....But my daughter was away travelling at the moment, just trying to get a week in a place or two days in a place and she's had enough of it so she'll soon be back.

Cora's daughter's experience of travelling as becoming more difficult and therefore less enjoyable was mirrored in Orla's (a Romany Gypsy) accounts. Orla has lived extensively on the road throughout her childhood and into adulthood, yet she has noticed that throughout her life it is becoming more and more challenging to maintain a nomadic lifestyle:

It's getting much harder. You could be moving...probably you could start moving at...they could move you at 6 o'clock morning and you wouldn't stop. They wouldn't stop leaving you probably until 11 or 12 o'clock at night.....

These consistent challenges towards a nomadic lifestyle have affected her perception of travelling to the degree to which she has now opted with her family to live on a permanent council maintained site. She now only travels for short periods during the school holidays. Therefore Orla's experience reflects a variation within this constituent, as she was the only Gypsy/Traveller whose preference was living on a site rather than travelling:

I like it on here (living on the site)...Yeah, and I've got like...I've got six children, so, like...I mean, if you're on the road side, there are no baths, there are no toilets, there are no schooling for the children. So, yeah it was hard life.

Of all the Romany Gypsies I spoke to who were missing the ability to travel, the most traumatically affected by this was Rawnie. Rawnie was 23 years old and was living with her Gypsy husband in a permanent council maintained Gypsy site. They lived in their wagon with their young son who was just a few months old. Rawnie became upset during the time we spoke together, reflecting upon her life in the past

when she travelled extensively with her parents, her life now as a mother, and pondering upon the future life of her son. Rawnie explained how the inability to travel was having a negative impact upon her mental health, and how she felt forced to move onto a site and pressurised to give up her travelling ways which to her was incongruent with her values. She was living inauthentically:

I miss travelling and being allowed to stop places. It's been a while (since last travelling). I haven't moved. It makes you very depressed, I think, when you don't. It makes you feel very...it makes you feel trapped. You need...you want to go. Because it does, it makes you feel very depressed and you wonder...because you get sick.

If we try and move, say, if I wanted to move on the top of the slope, by now, I'd get police to me. I'd get...because the farmers there and everyone in their houses. They'd ring up, "Oh, my God. There is a Gypsy." You don't get no...nothing. You don't get anything. You don't get leeway, nothing. You don't get a choice. You get forced to live on sites.

All of the participants I spoke to identified that travelling was not just a simple activity that they did. Rather it was an integral part of who they were; an embedded aspect of their culture and their self-construction as Gypsies and Travellers. Whilst Alanna (Romany Gypsy) could understand why people in the settled community/Gorgi did not like Gypsies/Travellers travelling and pitching up at the road, she felt that alternative provision should be in place to ensure that both sides were not disadvantaged:

It must be frustrating for people that we're just pulling up at places. But if there were more sites made for you to travel to, maybe more non-permanent sites just for people to do stop offs on, then it wouldn't be that way, would it?

For many of the participants, being able to travel was at the core of who they were. Therefore not being able to travel meant that they were living inauthentically and were somehow invisible within mainstream society as their norms and cultures were not recognised and valued. The participants expressed a feeling of not being free to live the life of their ancestors and previous generations, instead they felt pressurised to adapt to a more settled existence:

It makes me feel bad. I mean, it's my whole way of life innit, its generations my people lived down the road and it's just, we've got to believe that god made this earth not for people to have little sections

of it on people that you know, he made up for everyone. He gave it to everyone. So, we believe that we're allowed to roam wherever we want to go you know without persecution that all we do get when we're on the road – Jimmy (Irish Traveller).

...all we want to do really is to go out and travel and try and do like ...whatever we've been fetched up to do. Do you know what I mean? And when you're forced not...you are forced not to do it - Rawnie (Romany Gypsy).

Another aspect of a vulnerability of feeling pressurised to conform to living a certain way was with regards to education. Many of the participants identified that education was important to them (Jimmy, Dena, Alanna, Nadia and Rawnie). However, the degree and level of education was perceived differently, with many participants wanting education to be more appreciative and flexible to accommodate their traditional cultural ways. Yet there was a sense that they were not able to choose the level and degree of education but that they had to change who they were, their beliefs and identity to fit within the expectations of education in wider society:

Yeah, and that is one of the good things now about school, that's a very big thing with Travellers we realise ourselves. I learned myself more or less to read and write. But this day and age because of computers and this and that and kids have got to learn it. They've got to...that's one of the biggest things that Travellers want now for the children to have an education for only...you know, but then, and do the computer and things. But certain age out, gone, you know what I mean, otherwise they'll get too many country ways about them – Jimmy (Irish Traveller).

You can't take them out now, like you did years ago. You can't... and if they come out you have to have a tutor as well. Every day, you are teaching the children so that's what they do. They get a tutor. It's £20 an hour, probably something like that. But you have to do it or you'll be arrested over it – Dena (Irish Traveller).

If I had a choice or say, I'd go and travel and just come back for a winter place. But obviously, it doesn't work like that because you've got so many rules and regulations now. You got to be like tied down. I'd like him to have his education. I had my education. I can read and write...I finished school, done my GCSCs, and everything, and I still travelled. I still had that Gypsy life. So you can do it. It's just when people are getting a lot stricter now. You can't do anything now. You can't...if you wanted to move somewhere and teach your...obviously, the boy in there, and you want to teach him that way of life, you can't because then you got so many rules and regulations and they're trying to get you back. And then, you're frightened of your own being taken away from you – Rawnie (Romany Gypsy).

I like to do that (travelling) because that's the way of our life...and it's good to show your children your way of life also. So that's why the schools should understand when you go away for a few months or so. They should be acquitted with like homework and stuff for them to do because that's the way of our life. They shouldn't try and stop that – Alanna (Romany Gypsy).

I'd like him (referring to her son) to, like, you know, know his roots, know, like, the history of everything and things like that, like, his dad and things, they're used to, like...with horses and things like that!" And, like, I'd like him to learn to deal with horses and things like that - Nadya (Irish Traveller).

For Jimmy (Irish Traveller) whilst he believed an education was important he also perceived that it was important that Gypsies and Travellers are able to educate their young into their ways of being, their ways of working. For him, young Gypsy men learnt their identity as Gypsies or Travellers through working with the males in the community, as restricting this results in the community having to change who they are and contributes to a sense of a changing identity:

By the time a child is 12 or 13, they're out of school. That's normal because a travelling child is not like a country child. A 12-year-old country child is still a child. A 12-year-old Traveller is coming into manhood, they'll know as much as an 18-year-old country boy or country girl when they are that age because it is....I don't know what it is, it's something bred in us, I don't know.

Johnny (Romany) feels that this pressure to conform to a different way of living has also affected what he eats. Johnny recounted days of his past when he was living roadside, eating wild rabbits, hedgehogs and other wild birds. To him this close association of killing and eating your food was his way of living, yet he felt as though this was denied to him:

No freedom. I mean, you can't do this, you can't do that. You can't even have a fire outside..... We can't even have a cook fire on here." Yeah, yeah, yeah....the same as the hedgehog...they made him...you can't have hedgehog now (Laughter)....they've put the kibosh on them.

Many of the Gypsies and Travellers that live on the council maintained site have been told (as part of their tenancy agreement) that they are not allowed to have a fire on the site, due to health and safety concerns. Yet the impact of this upon the individuals is huge. For them it is yet another example of how they feel pressurised to conform to living a certain way, and this is having a negative impact upon their cultural norms and beliefs: another aspect of their culture lost:

We ain't allowed to have a fire outside. I miss that... the cooking with the pot on (Laughter). We miss that, my love, yeah (Laughter). I'd have a fire outside if they'd allow me but they won't allow it – Daisy (English Traveller).

Cooking outside, everything. Sitting around a stick fire, everything. Can you do that here or...Well, no, because if you'd make a fire, you get the fire brigade down and it gets wrong. So, no, not really. You can't do what you want. There are obviously too many rules and regulations you got to keep to – Rawnie (Romany Gypsy).

For Daisy (English Traveller) this inability to cook on an open fire impacts negatively upon her mental health, because she is not able to live her life her way and this makes her feel sad, *“I gets more miserable. True, you gets more miserable when you can't make a fire”*.

This inability to have a fire was not just experienced by those on permanent council plots. It was also experienced by Jimmy (Irish Traveller) who owns his own land. He was told by the council he was not allowed to have an open fire, and had to openly challenge this decision on the grounds of racial equality:

*When we first came here, we were told not to light no fires. And then ***** (names Race equality man) he got in touch with the council, write them letters and that and said and then they came down and said, “Okay, you're allowed a small fire and that.*

It is not just an inability to be able to have a fire which results in the participants feeling vulnerable due to a pressure to conform to living a certain way. Shauna (English Gypsy) has seen numerous changes over the last ten years living on the site, and these changes have been largely negative due to increasing restrictions for those living on the site. The site where she lives is due for redevelopment and she told me about future restrictions that were to be implemented regarding the ban of the use of Silkies or Traps, thus making more of her culture invisible and not seen. This for her was difficult to adjust to:

.... now with the plans that they've got going, they're saying no traps or Silkies on the site. But Silkies and horses are part of what Travellers are...

This sense of vulnerability linked to a pressure to conform to living a certain way, resulted in a sense of having to change who they are. Their lives as Gypsies and Travellers were in a constant state of flux. Yet these changes were not self-imposed, instead imposed by others external to the community. Shauna (English Traveller) expressed how she had seen the changes throughout her life *"It hasn't just gone from that way to the new way, the changes have been gradually and basically forced upon us"*.

7.2.2.1 Response of living inauthentically

There was a sense from the community that due to the multiple restrictions on their lives (inability to travel, and restrictions on site) that their ways of living are being eroded with little choice or say to halt the progression. This is moving them further away from living authentically (as they would wish) towards a more inauthentic but settled lifestyle which is resulting in them experiencing feeling vulnerable:

It's been a challenge from every which way, innit? I mean, the government challenges it. The individuals, the Gorgi as we call them, they sort of don't like us on their doorstep, sort of thing. It's...you got it from all quarters, you know? – Johnny (Romany Gypsy).

*There's Travellers in ***** (names town) that's been forced into houses. Nowhere to go, no money, they've been living on the side road of the road, all of them been put into houses – Jimmy (Irish Traveller).*

We're forced to do something, then you got no choice in the matter have ya - Rawnie (Romany Gypsy).

All our life, all our life...since as soon as I can remember we've been threatened our people is threatened...it's a way of life init... No matter who we are, Travellers or Gypsies, whoever you are, no matter who it is, and they say, "Have you ever felt threatened?" You felt threatened all the time – Jimmy (Irish Traveller).

7.2.3 Vulnerability of feeling split in one's identity

The next constituent related to a vulnerability that related to feeling split in one's identity. Some of the participants expressed a changing identity with regards to women in their community. A number of the participants (Dena, Alanna, Cora, Layla, Lizzie, Girlie and Orla) identified traditional gender roles within the Gypsy/Traveller community (the man being responsible for working and the females being responsible for the home and raising children). There was a different perspective emerging with two of the participants (Nadya and Rawnie), who felt they now had more options than their mothers traditionally would have had. However there was a sense that these opportunities needed to be balanced with maintaining yourself as a Gypsy or Traveller and staying close to your roots:

.... it's easier for travelling girls now. They've got more ambition to do things and they know they're allowed to...but years ago, like, it was just an abnormal thing to do.– Nadya (Irish Traveller).

...I think a woman, definitely a woman, should have their own independence some way or another. But like my beliefs and things I don't think that should change. See, I don't think college is a bad thing, and the job, I think that's good to have. But other than that.... Things like that, yeah, but not your ways. That they shouldn't change because that's us that's who we are. It's not just who we've been fetched up like. It's what we have in our blood. We can't change the fact. – Rawnie (Romany Gypsy).

This sense of a split identity was largely experienced by the younger female participants. Recognising that whilst there are increased opportunities for Gypsy/Traveller women and these were positive, they also led to conflict both within their own community as well as conflict with others outside of the community. There was a sense that some of the participants felt as though they were split between their own traditional worlds as Gypsy/Traveller women and as young women within wider society. This is demonstrated in three examples from three different young women:

Alanna (Romany Gypsy) is divorced (something which is not very common in the Gypsy/Travelling community); she lives in a wagon with her young son, on the same site as her brothers. Even though she is in her early thirties she has resigned herself to living on her own, as she cannot date or enter another relationship again for fear of bringing shame to her family. Therefore whilst she was free to remove herself

from her marriage, it was not a decision she took lightly knowing that even today she would be frowned upon within her own community for her decisions:

I'm divorced. Yeah. They find that so amazing, because it's not very common for a Gypsy to be divorced. And that's becoming more popular now days where back in the day; people live together until they died sort of thing. Now, it's been more popular that.... yes, yes. I do feel different... I don't have a lot in common with these now (referring to other Gypsy women present) because these are always with their husbands. If I go out and stuff, obviously I can't do what non-Gypsies do because I will get.. like scandalised, you know. I get a very bad name. So yeah...It's very hard for me now. I can't move forward now, if I'm not allowed to marry again...It does happen, but I've still got a very...a lot of old-fashioned ways as well. It is happening a little bit I suppose...but it's still a scandal to a lot of them when you remarry. So I wouldn't remarry. So I have to leave everything to myself. I'm not allowed to have a boyfriend as well. Yeah. I'm not allowed a boyfriend.

Layla, an Irish Traveller, is also divorced having been married to a person from the settled community. Layla's family accepted her decision to divorce and support her in choosing her career choices. She previously attended university and is currently in college. Her sisters feel that of all their family, she is the most like a country girl. However Layla is aware her choices reflect not only on her but also her family:

I think I do sometimes, but then I think to myself, like, I stayed with him for eight months and, like, it was very bad. He tried to stop me seeing my family...and I wasn't...like, my family are too close. I put it for eight months and I physically couldn't take anymore, and especially being away from my family and that. And now I think people can think what they want. Everybody is going to talk, it doesn't matter what you do, whether I stayed with him or not. So, I think like...Yeah. You just...you learn it's more accepted now. It is not accepted fully but it's more accepted.

Our immediate...they know our family has. Some people, like, all different mixes of Travellers will look at it different. Some will think it's disgusting, it's wrong; she should've made her marriage work no matter what. It's the way, they have children and put up with their husband and all things like that...but whereas, like, it was easier for my sister because she had her own way of working, her own way of making money – Nadya (Layla's sister).

Lastly Rawnie (Romany Gypsy) has tried to integrate and live within both worlds. When she left school she was keen to go out to work because she wished to learn

how to drive and required driving lessons. Yet her desire to go out to work was met with suspicion and dislike from her community who accused her of becoming “Gorgified”. Whereas at work, once her colleagues found that she was from the Gypsy community, she found herself being ostracised from her colleagues. For Rawnie this made her feel as though she was separate and detached from both worlds, being torn in two because of her desire to work. This was very frustrating for her as she felt no matter what she did she was damned for doing it by both communities:

....because obviously it's trying to pull them out of their own community and put into another community, a strange community, like.... So, let's say I'm going to work, they say, "Oh, you're going with the Gorgi's, mixing with the Gorgi's," and things like that....and when...like, say, one of my friend had picked me up from work one day.....And you'd have everybody waiting outside at 2 o'clock we used to finish and everybody would be having a fag outside, all chatting, and they'd all dress up and stare like you're an alien. Just weird, like, they'd stop and stare at my friends. I obviously did get a bit funny like...like, the Gorgi's would be staring my pals and think and just...I don't know, like, weighing them up.

So, I was like stuck in the middle, you know, tormented all the time like from both....

....but what aggravates me now is, do you know like when they say time is changing and it's modern, and you've got to, like.., get in with it, like, sort of thing. You can't just be...It will never change. So if we're trying to modern then, and we're trying to fit in and we're trying to get jobs....Why aren't people accepting us if we are trying to accept that we've got to get modern? We can't stay old-fashioned all the time.

From these examples, there appears to be a sense that opportunities and choice for young Gypsy/Travelling women can be at odds with their embedded cultural views regarding the roles of men and women in society. Rawnie no longer works (since her marriage) and is now a mother of a young son. She appears deeply unhappy with her marriage, and yet feels she had no choice but to stay in a relationship, due to her Gypsy beliefs that you do not get divorced:

Yeah, you move with your husband's families, and you're not allowed to divorce. Not really. It's not for the want of another man. It's just...it's just, I don't know.... (How she would be viewed in the community) like she's a tart, a common tart, she must want another man sort of thing. And obviously, a Gypsy woman has got to keep respectable...I don't want to be a disgrace on my family or bring a shame on my family and on his family. I don't want to put shame on

nobody's...both sets of the family. So a woman's job is to keep the home going, not a man, like...not keep the woman or put food in the cupboard and things like that but ... I mean, like to keep it together. That's what you should do for the sake of your children, if anything else.

In Phase 1 of this study whilst talking generally about experiences of vulnerability in order to ascertain the breadth of the experiences of vulnerability of Gypsy/Travellers one of the participants, Christine, a Romany Gypsy in her thirties, spoke about her experiences of feeling torn between her culture and the wider opportunities available to her:

Some of them used to take the mick (about her going to college), saying you know you want to be a Gorgi...So the roles almost reversed who was having a dig. Do you know what I mean? And they saw that I wanted to leave my family and Romany life behind and become a Gorgi.

When my dad went into hospital that I felt the most vulnerable in my life really and the most torn with what I know as a nurse and what I should do as a Traveller girl. The two just don't, they just don't meet in the middle and it does cause hard work for me.

These quotes add confirmation to this particular constituent of feeling split on one's identity as it is clear from reading Christine's accounts that at times she feels split between her traditional values as a Romany Gypsy woman and the opportunities and her role within wider society.

7.2.3.1 Response of complexifying one's identity

This split in one's identity has led to participants responding by having an increasingly complex self-identity, which has largely occurred through increased integration between the Gypsy/Traveller and Gorgi/settled community. Due to this, tensions arise for some individuals; between their wishing to follow their "traditional" cultural values and wishing to embrace aspects of a new identity due to new opportunities and increased exposure to different cultural ways of being. This has made it very challenging for some individuals, and yet the occurrence of complexifying one's identity is likely to increase in the future due to the increased integration between the two communities. Feelings of the participants towards this increasing integration were mixed; some of the community felt uncomfortable,

expressing a desire that the community stay within the community (Johnny), whilst others (Daisy) identified that Gorgi who marry into the Gypsy community, adapt to travelling ways:

A lot of...it's what I was saying back a while ago, the Gypsy is being bred out. You get like Gypsies marrying into the Gorgi community and stuff like that – Johnny (Romany Gypsy).

I've got a sister who married a Gorgi, and they turned the same as we with the caravans...They'd never travelled before. But when they got married.....they started travelling ...and joined the family and did travellin. – Daisy (English Traveller).

However there are cultural variations between the Gypsy/Travelling and the settled community which can make it hard to adapt, especially when a female Gypsy marries a man from the settled community. This links to gender roles, as can be seen from Layla (who married a country person):

You think on the otherside, there isn't really that much difference; you've just got to learn their ways of living and stuff but there's just so much...even the tiniest little thing like housework, it could cause such a big rift between you and your husband that way. Like, whereas travelling boys a lot of them– not all of them, a lot of them – believe in not doing anything like, letting their wives literally serve for them, which is wrong. But, like, where some country boys especially her husband he didn't mind the fact of if he mopped the floor or washed up or make a cup of tea. Things like that, he didn't....And I don't know, sometimes...and then when he'd mix, like, with our family, and out travelling husbands and things and they kinda laughed upon that. And then it cause the rift between their relationship – Nadya (Irish Traveller).

7.2.4 Vulnerability due to feeling a loss of one's heritage

The fourth constituent was a vulnerability that arose from a feeling of loss of one's heritage. Previously identified in the second constituent (vulnerability related to feeling pressurised to conform to live a particular way) there is an increased inability to have a fire in both council maintained sites and for individuals living on their own sites. A fire for the participants is not just a functional activity but symbolic and integral to their cultural being. Shauna (English Traveller) spoke with longing of her childhood when all of the Gypsies on the site would come together over a fire. She expressed feeling that through this she experienced a sense of belonging to an extended community, as they would share stories and sing songs. Yet now this very rarely occurs and as a result she feels as though this sense of community has

become lost and the individuals on the site have become more isolated, more invisible to each other. This lack of ability to have a fire also has implications for the future generations, as Gypsy/Traveller heritage is largely shared through stories thus not having the opportunity to share these stories will mean in the long-term that their shared history will become invisible and lost to future generations. This sense of community isolation and loss was also expressed by Johnny (Romany Gypsy):

We got together and we felt one big happy family. We all used to come out. We'd have big bonfires...all used to join in. We used to have families come far from other sites... Shauna (English Traveller).

It's just the sadness...everything's...the culture's lost, if you know what I mean. It's just a simple thing to...Travellers used to have fires outside, safety, like a big tin and everything. Even that's gone. They all used to come out and sit around the fire, have a good chat. But there's nothing now. It seems everyone is closed off into their own little rooms. We don't see no one - Shauna (English Traveller).

And you sit there and ran a fire of a night time, have a chat, and talking about the old times, and things like that, you know? - Johnny (Romany Gypsy).

I mean.... A lot of the Travellers can't look up in books to see their past because they can't read or write. So the way the Travellers pass on...their heritage basically is word of mouth around a fire – Shauna (English Traveller).

Another example of the vulnerability experienced by this loss of one's heritage is regards to the use of the Romany language. Shauna (English Traveller) reminisced that during her youth many Gypsies and Travellers would converse in Romany. Yet now it is a language that is not often heard, especially in the younger generation who typically speak in English which she feels will lead to the death of their language:

You don't hear it as much. No, no. It's a shame really...It is. You don't hear it. I mean, I go and visit some families now. They might say something out of the blue and I'd say, "I don't know what it is," because we don't talk it. And there were things, now, perhaps I heard it when I was 3 or 4 year-old, and it comes out all of sudden and you think, "I've heard it before but I don't know what it is," because it's gone.

All participants identified a strong sense that their way of life as Gypsies and Travellers was coming to an end. At the heart of this was the inability to travel, be nomadic and follow their cultural norms as identified in the second constituent (vulnerability of feeling pressurised to conform to live a particular way) resulting in

the vulnerability experienced due to feeling split in one's identity (third constituent). There was a real sense from the participants that not only will the future see no Travellers on the road but there would also be no Traveller sites. Instead they will be forced to live in bricks and mortar. This contributed to their sense of vulnerability, due to a loss of their heritage and their way of life, leading to the eradication of their people:

...well, it's finished now, Gypsy life anyway - Johnny (Romany Gypsy).

But I do believe there will be literally no Travellers. Everyone will be in houses, everyone will be settled, and everyone will be mixed – Nadya (Irish Traveller).

I think the way of life is dying out anyway – Orla (Romany Gypsy).

I think Gypsies will be a bit like dinosaurs...dead and gone – Alana (Romany Gypsy).

Well, it's all changed, because there are no Travellers on the road then. They're all on the sites. On the road, you can go anywhere and meet the caravans coming. But now there's none of that. And none of our people are on the road now. They're all on the sites. – Daisy (English Traveller).

It's just completely gone, give it another, not even 10 year and you won't see a Traveller, you won't see them on the road anyway – Jimmy (Irish Traveller).

7.2.4.1 Response of Mourning

There was a sense of sadness regarding these changes. For Johnny (Romany Gypsy) this sadness arose from reflecting upon his life as a child on the road and the challenges he now faced whilst trying to maintain a nomadic lifestyle:

I do get a sense of...well, I don't know how to put it...forlornness or something, I suppose that's how to put it, something like that. When you think about what you've done in your lifetime and what you can do now, try to compare the two and it's frightening really, very upsetting really in a lot of ways.

This sadness was not only due to reflecting back upon their own lives and the changes they had seen, but also in consideration of the lives of future generations. Daisy, an older English Traveller, reflected that her cultural heritage is almost alien to her granddaughter and she mourns for the loss of her culture that future generation will never see:

Well, it seems to me, all of the old fashioned people's gone. That we know all the older ones.... There's all youngings now... There ain't many older ones have left. Everything has already changed. Yeah.

7.2.4.2 Response of a resisting rebellion

As well as a response of mourning and sadness for the loss of their life that arose from their experiences of vulnerability linked to the loss of one's heritage, there was also a response of a resisting rebellion. There was a clear sense of living inauthentically "not being able to live the life I want to" which was keenly felt. Yet the urge to live the way of one's history was so strong that many of the participants admitted to breaking the rules by having a fire in secret. Cora (English Traveller) waits until the wardens are away and then puts her pot outside to cook on an open fire. She is only able to do this infrequently however, and covertly, knowing that in doing so she runs the risk of getting into trouble with the wardens and the council "No, because when the wardens are out, I like to put the fire out (Laughter).....I keep my way of going so next time I shall have a fire outside when our warden has gone away for the weekend".

7.2.5 Vulnerability of feeling discriminated, persecuted and threatened

The fifth constituent links to the participants' experiences of discrimination, persecution and being threatened. This is not simply a manifestation of being defined and homogenised in a particular way. The former identified a vulnerability linked to being treated as a homogenised group rather than reflecting individual cultural identities whereas this constituent is linked to a vulnerability associated with feeling persecuted and threatened. All of the participants had experienced racism; being discriminated against on the basis of their cultural identity. This manifested in a variety of ways. For some participants (Cora, Orla, Johnny, Rawnie, and Alanna) they had experienced being refused entry into pubs and clubs. Johnny had experienced the use of racial language (being called a pikey) a term highly offensive to him. Whereas Rawnie and Dena had experienced having stones and eggs thrown at their caravans and Jimmy (Irish Traveller) had his post box shot at six times with air rifle:

"No, they treat you, class, all as one thing. All of you are the same. Very racist, I think it's very racist, very racist" Rawnie (Romany Gypsy).

"We're not treated fairly. We're not treated fairly, not by...from any quarter really, not from any quarter" Johnny (Romany Gypsy).

They would call you Gypsy and a lot of shops wouldn't serve you – Cora (English Traveller).

As soon as I got there, they said, "You're not coming in." and I said, "Why is that?" "Because you're a Gypsy." "So, you're telling me I can't come in because I'm a Traveller?" He said, "Yeah." - Orla (Romany Gypsy).

I've seen pubs with signs out 'No Gypsies' – Johnny (Romany Gypsy).

...every time you're on the road, you have things chucked at ya, stones chucked at ya home...You have big bricks put through your window and things, and people coming on it, 3 and 4's o'clock in the morning, trying to smash you up, – Rawnie (Romany Gypsy).

...you get people coming by shouting and hollering, Gypsy and saying pikey, with their horns going in the middle of the night, trying to wake you up. – Johnny (Romany Gypsy).

Every mornin you get up and the caravan's covered in eggs, full of eggs. In winter you couldn't hear them, with the wind and all that. It was very tough. You feel terrible when you get up in the mornin and there's all eggs stuck to your windows and with the caravan it's so hard to get off. But that continued for a long time. – Dena (Irish Traveller).

The participants identified a dichotomy between their experiences as an ethnic minority and the treatment of other ethnic minority groups. It felt to them that other minority groups are afforded a greater degree of protection than they are. They noted a synergy between their current experiences and those historically of other ethnic minorities who experienced oppression in the past. They identified that it is somehow acceptable to be racist towards them, however if this occurred to any other ethnic minority group there would be repercussions. This led to a sense of not being valued, that they are not afforded the same rights and respect:

But it's like other people's got right like other religion's got rights to wear those things across their face, the Muslims, and things. Obviously, blacks can't change the colour of their skin. They're accepted now...they were slaves a hundred years ago, weren't they? But they've got their rights. We've never had rights like it... Every other race, they might be getting on fine, but for us it seems were stuck in a rut...nothing has changed – Rawnie (Romany Gypsy).

Who were they to refuse me, because if it was an Asian...They couldn't discriminate Asian people...yet every week, for about five

years, on the same club, they looked at me and told me I cannot come in because I'm a Gypsy – Orla (Romany Gypsy).

I mean, if it was a black man, they couldn't say 'No blacks', could they? ...they wouldn't be able to say to them what they say to us and get away with it, or any other ethnic minority. They just wouldn't get away with it. They'd get locked up. But it's alright for them to do it to us – Johnny (Romany Gypsy).

...like, a Muslim family come in, and they pretty much lived in the hospital, and they didn't get talked about as much as...because of their fear of racism and stuff. But they didn't get talked as much as Travellers do. Funny old world – Layla (Irish Traveller).

I don't think Gypsy is being accepted as such yet, a lot of negative throw back at them. We're like...we're something like the blacks were in the slave days. We haven't come forward – Alanna (Romany Gypsy).

Yeah, Travellers aren't classed as being against...we can't go to the police and report that we've been called racism by a gang of people in town whatever, as much as... – Girlie (Irish Traveller) a black person – Layla (Irish Traveller).

This discrimination, persecution and feeling threatened manifested not only in social setting (such as shopping and in pubs and clubs) but also within institutional settings. Within education, participants identified issues regarding bullying of young Gypsies and Travellers especially in the secondary school sector. Two of the participants (Shauna and Orla) had witnessed bullying in the school system to such an extent that they felt the only option available to them was to remove the young people from school system and home educate:

My nephew got bullied quite a bit. He threatened to kill himself. It didn't happen, thank God, but they had to take him out. The teacher wouldn't listen; she kept saying there was no bullying at school. – Shauna (English Traveller).

My girl went to the comp and then in the end, she was eating the food in the toilets. I refused to let her go. I refused in the end. I rang them up...- Orla (Romany Gypsy).

There was occasions where some people, when they knew that you were a Traveller, they, like, you know, say stuff...- Layla (Irish Traveller).

Experiences of discrimination within the educational system was also identified with Phase 1 (breadth phase) of the study. Both Mary (Romany) and Mary (Irish Traveller) identified feeling discriminated against at school by both other children

and staff. However in Phase 2, this discrimination was not just located within the educational institutional settings but also within hospitals and the police. Layla (Irish Traveller) works in a large acute hospital as a healthcare assistant. She described that during the context of her work she would often witness the deleterious way in which Gypsies and Travellers are spoken about by nurses and doctors saying, “*If Travellers come in to be treated, like, you should hear the things that they say*”. Whereas Jimmy (Irish Traveller) experienced discrimination from the police force as did Cora when she was travelling:

The police...they were more or less as bad.... When we first came here, for the first year and a half being here, at 3 o'clock in the morning skidding around with sirens; Then no matter what motor that went out, it was pulled up, even though, maybe they came the day before and you'd showed them the licence and that...but every day that you went out, you are getting pulled over four or five times – Jimmy.

But it did used to rattle our cage because the police choose to be bad when we used to travel around, because they wouldn't think no more and kicking a fire over you – Cora (English Traveller).

The participants also expressed feeling discriminated against in the workplace. They perceived that as soon as colleagues found out that they were Gypsies/Travellers then their attitudes and behaviour changed towards them, often in a very negative, passive aggressive way. Whereas before they were acknowledged and had friends, now suddenly no one spoke to them, almost as if their existence and presence was denied. When they were spoken to, it was often to be identified as a scapegoat if any issues arose in the workplace. Thus they became isolated which perpetuated a feeling of not belonging and not being valued. This became so overwhelming that it resulted in them leaving the paid employment:

And then she told other of her colleagues that I was a Traveller and whatever, and then their way kinda of changed...and then when certain things went missing in the workplace....Because I was a waitress, and their tips went missing, and money, things like that, I always would become the first one that was going to be pinpointed for that – Nadya (Irish Traveller).

...I had a girl stopped talking to me in the factory. Well, they was a woman, like 30 years olds and they stopped talking to me, wouldn't look at me, I don't know, always give me funny looks – Rawnie (Romany Gypsy).

I got the job (working as a school cleaner) when the headteacher was away on leave...she wasn't happy for me to be at school. She would never, hardly speak to me. They went out Christmas time, I never got invitation, everyone else did, the other cleaner did. I was always left out. I was sad to leave my job – Shauna (English Traveller).

Some of the participants expressed a sinister undercurrent to the recent legislative changes and the forced adaptation into a more settled culture. For them, this reflected genocide; the eradication of their people by wider society. The participants made comparisons between what is happening now and what happened during the Holocaust in the Second World War, arguing that this forced adaptation is really no different to what Hitler tried to achieve. Yet there was also a sense that they were powerless to stop this death of their people, the eradication of their way of life:

The way I look at it they're trying to wipe out the Travellers all together – Jimmy (Irish Traveller).

I think they're trying to do something what Hitler tried to do, really: ethnic cleansing. I think they're trying to drive us all into the sea and say, "That's it, you know, end of that." – Johnny (Romany Gypsy).

Well, they're trying to...how can I put it; Gorgify us if you like to put it that way. I don't know what else to put it, really. They're trying to tame us (laughs), like they did the Red Indian, you know? They're trying to civilise us – Johnny (Romany Gypsy).

Looking back at the findings from Phase 1 (breadth phase which explored the range of experiences related to vulnerability) the participants in this phase also expressed a sense of ethnic cleansing and the death of their people. Thus further supporting this psychological sensitive variation (eradication "the death of us"):

Most Travellers have settled down one way or another now – Tommy (Showman).

Because you know the Traveller way is certainly dying out – Christina (Romany Gypsy).

Because all the government now is trying to do is to stop planning so that they can put us in housing and hopefully we will lose our identity and behave and be one of them eventually. That is their aim. ..there is a sinister element here that we are going to go through another ethnic cleansing – Issy (Romany Gypsy).

In years to come there will be no Travellers, no offence but people like outsiders are just going to try to erase Travellers to get rid of them like we were never there – Mary (Irish Traveller).

7.2.5.1 Response of hiding (who they were)

As a result of their experience of feeling discriminated, persecuted and threatened on the basis of their cultural identity, most of the participants responded to this by suspending their identity, hiding who they are. They chose not to share their Gypsy/Traveller identity outside their own community because they feared that this would result in them experiencing discrimination, almost as though to be accepted one has to deny who one truly is:

Well, I am a Romany but.... When it comes to paperwork, you always put English, don't you? (Laughter) – Shauna (English Traveller).

...because we always keep it a secret that we are Travellers – Layla (Irish Traveller).

...Gypsies try not to say at all – Alanna (Romany Gypsy).

...even though people probably know there's just something different about you, you always try and hide that – Nadya (Irish Traveller).

This sense of having to hide who one is was not just restricted to completing forms. It also occurs in interpersonal relationships between individuals and members of the settled community. Many of the participants expressed how they had learnt throughout their lives to hide their Gypsy/Traveller status as people would treat them differently once they knew they were Gypsies. An example of this is presented by Rawnie (Romany Gypsy):

Well, one day, I got myself a job. I was 16-year-old and I never told anybody...I worked in the factory and I never told anybody that I was a Gypsy or anything. And I kept it quiet all for months. And then, because I never really communicated with anybody in work, so I wasn't really...I wasn't really allowed to talk to anybody. I was only allowed to like work and come out. They found me a bit suspicious, like...like a bit funny. And one man followed me home, because my dad picked me up because I wasn't allowed to walk, followed me home. And when I went back into work the next morning, everyone was saying, "Oh, Rawnie, you're a Gypsy. You're a Gypsy." And I got tormented for...I was working there for about four years...nearly four years. As soon as they found out, I got tormented and tormented every day of my life, tormented, tormented. "Oh, she's got a new pair of trainers. Oh, no, she's still stole them, you know". All, things like that, and I was just working the same as them. And it made me feel a bit...I don't know, a bit insecure about yourself like...

As a result of these experiences of being treated differently once people knew they were Gypsy/Traveller led individuals to become much more cautious, only

disclosing who they really are once they feel there is established trust in the interpersonal relationship, this is if they choose to disclose at all. Take Orla for example, “I got a lot of non-Traveller friends. That’s only because they knew...they didn’t know what I was for a long time until they’ve got to know me and then, they found out what I am and then it’s just...I’m a friend”. This experience of hiding oneself and being treated differently once their Gypsy status is known helps us to understand the self-segregation that was identified in Phase 1 (see chapter 5). In the life-world experience of insider identity, participants in Phase 1 expressed a desire to stay within one’s own kind, feeling safe and secure with one’s own people. However in this Phase, some of the participants had experienced being shunned by other Gypsies/Travellers who have become more settled (who also wish to hide their identity). These Gypsies/Travellers have chosen not to speak to Gypsies and Travellers living on Gypsy sites for fear of becoming exposed to the settled community:

It makes you think from a different perspective, like all non-Travellers. Like, I suppose the way they think about us sort of thing, like when we get that glimpse of them, you see the bad side of them. And that’s why we don’t really communicate with non-Gypsies. We prefer to stick to our own. We know where we stand with our own – Rawnie (Romany Gypsy).

You know, you could go down the town there and there’s a lot of them all made up, lipstick, powder, and you know they won’t talk to you on the street, you know what they are, and they know you know what they are. You know, but the make out Gorgis, they won’t speak to you too in the bingo. The make out ones...Yeah, they once stayed here. Because they don’t want to say they’re Travellers. You know they’s keep on side on their own - Cora (English Traveller).

There are distinct nuances within this constituent, as some individuals expressed they did not hide who they were, instead they were proud of who they were and chose to make their status as a Gypsy or Traveller transparent whatever the consequences:

I grew up as a Gypsy and went to school obviously and things. And I knew that you could be judged and things, but I was never ashamed of who I am. I think it’s some part of us that I don’t know where it comes from that just keeps us not ashamed of who we are – Alanna (Romany Gypsy).

For Shauna (English Traveller), being open about being a Traveller is a self-protecting mechanism, she would rather be direct and honest at the commencement of a relationship rather than emotionally invest in making friendships with people who may later ostracise her when they find out she is a Traveller:

...there's nothing worse going in somewhere and they find out who you are and you feel they're changing. That's when it hurts.

So, they know who I am...so I haven't got to live two worlds, if you know what I'm trying to say. I haven't got to be a Traveller at home then when I go through them doors; I've got to change to be part of what they're doing.

Yet for Johnny, even though he is open and direct about his status as a Romany Gypsy, he does feel the need to justify his status and to identify himself as different from the negative homogenised discourse surrounding Gypsies and Travellers, “I always say that I'm a Gypsy but I'm not like all the others. I don't steal things. I don't go around driving with no insurances and taxes and things like that. I'm a Gypsy but I don't tell lies”.

7.2.5.2 Response of Mourning

As well as a response of hiding, there was also the response of mourning and sadness especially with regards to feeling persecuted as a race. In addition, the participants mourned in response to their perception of their pending death as a cultural group especially with regards to the younger generation and for the life and culture that they would lose:

It was way of life innit....which is coming to an end, the end of an era...But I hate to think what my grandchildren or my great grandchildren, I hate to think what will happen by the time they get sort of like middle aged or even past their teens really – Johnny (Romany Gypsy).

...yeah...it's died out. So, imagine when our babies get older, I reckon it will be really non-existing – Orla (Romany Gypsy).

I think it's sad. I think Gypsy's life should be kept going....because we are individual people. We should...I mean, it shouldn't die out, should it? – Alanna (Romany Gypsy).

7.2.6 Vulnerability of powerlessness

The last constituent relates to a sense of powerlessness regarding their future, of having no say and no voice. Daisy and Cora (English Travellers) spoke of their sense of powerless regarding their immediate environment. They are both living on council sites due for redevelopment, yet neither felt as though they have a voice in the changes being proposed. The changes were occurring around them. There was a sense of “this is how it is” and they had no choice but to accept that:

...they built that (pointing to a concrete building). We had an allotment here. They (the council) took it away and built that. You've got to beg for things. You've got to beg for it – Daisy (English Traveller).

I felt we've been...I'm going to be honest, lied to from the start. I will be honest. We were told at the start that it was like... Pod or chalet, we could choose. But now, it's just the one choice, “Well, you haven't got a choice. You got to have this Pod thing.” – Shauna (English Traveller).

This sense of powerlessness also manifested with regards to the discrimination they face. Instead they perceive they have no choice but to accept that this is the way it is. Both Orla and Cora (Romany and English Gypsy/Traveller respectively) spoke about how they felt humiliated and angry by the way in which they were treated:

Well, it belittles you. It belittles you, doesn't it, especially when there's...yeah, especially when there's a queue of people behind you and they're telling you can't come in because of what your race is – Orla (Romany Gypsy).

Well, it made me feel bad because the same blood runs from everybody's body. And we're all white and we're all English. So you know, it did used to make us feel bad – Cora (English Traveller).

Dena, an Irish Traveller, is both a mother and grandmother who verbalised that she was accustomed to being treated negatively because of her Traveller status stating “I don't mind, I've gotten used to it...Followed round, we accept that wherever we go”. However later in our interview she indicated that she does not go into the local village and socialise because she knows she is not wanted and says “We don't go anywhere. My nerves can't keep taking it”. This suggests, that contrary to her earlier statements in which she identifies it does not bother or affect her, at a deeper level it does, perpetuating her sense of vulnerability and resulting in her restricting her activities to avoid experiencing this. It's almost as if thinking about it is

overwhelming and therefore in order to protect herself from the hurt she tries to brush it aside and not think about it. This feeling of powerlessness “it is how it is” is shared among the community as children are often brought up not to challenge these negative perceptions for fear of further reprisals. Dena acknowledges she told her own children “*not to bother as we’s be the ones which would be arrested...they won’t be arrested and we’d be arrested. It’s not worth it so we tell them to ignore it*”. Girlie (Irish Traveller), another mother, acknowledges “*every Traveller you talk to, every one of them will just say, just accept it*”. This powerlessness perpetuates the discrimination and therefore vulnerability.

For the participants, there was a sense that neither they, nor their culture matter to people in the settled community and therefore what would be the point in challenging it as they would not be afforded to the same rights. Nadya, an Irish Traveller questions what would happen if she went to a police station to report someone for calling her a “pikey”, and wonders whether anything would be done about it:

You’re just being really stupid if you went in and reported someone for saying that you’re a dirty, smelly pikey. You know; you’ll wish you hadn’t called and reported, because you just know that nothing will be done about that.

As such, what would be the point of speaking out as people are not interested in hearing their voices; they do not matter and are not important because people do not care. So instead there is no choice but to accept it and live with it:

It boils down to the fact that our ways, and our culture, doesn’t matter. Our way or nothing that’s what we get, you know. Because some....I mean at the end of the day sweetheart, it’s a case of live with it, or get going – Lizzie (Irish Traveller).

It’s no good saying why are you doing this as we’re blamed, we’re blamed straight away. We’re blamed coz were Gypsies – Jimmy (Irish Traveller).

7.2.6.1 Response of Resigning

In response to their sense of vulnerability of powerlessness there was a sense of resignation that they had to accept the way in which they were treated, that they felt unable to challenge or question this treatment in any way. There was a sense of futility: that challenging the negative perceptions of Gypsies and Travellers held by

the settled/Gorgi community is futile and that instead one should learn acceptance, that one has to learn to live with and accept the negative comments:

They torture... I've kinda of come to terms with it. I know that we're not one of them. Nobody loves us, except for ourselves, except god... You know ...its part of life, there's nothing you can do, you can't make people like us if they don't want to like us, you know - Jimmy (Irish Traveller).

I was like, what could you call them back? You know, you couldn't call them nothing back, so we used to just take it on the chin – Cora (English Traveller).

You hear it and you see it, and what they say about other children as well, that are Travellers. But that's...you just learn to accept it, don't you? - Layla (Irish Traveller).

I admit it would make me very angry. And I felt like, I don't know, very frustrated that I couldn't do anything, like, about it – Rawnie (Romany Gypsy).

7.3 Essence of Vulnerability

At the heart of the descriptive phenomenological method is to derive at the essence of the phenomenon, the aspects that are invariant across specific situations (Todres and Holloway 2004). Following the presentation of the constituents of vulnerability experienced by individuals within the Gypsy Travelling community, here is the essence of their vulnerability.

To feel vulnerable as a Gypsy or Traveller means to become invisible existentially within a world of mainstream society; it is associated with feelings of being lost with no direction and no future. In addition to having no future one almost also has no present; as one is living in a world which sometimes discriminates, persecutes and threatens you, making you feel as though you are not human, something which must be eradicated and destroyed. Yet all that is wanted is to be left alone to live the life one wants to live. Instead one is pressurised to conform to live a particular way contributing to a loss of one's heritage. As such one cannot live authentically, in a way that is important, following the path laid out by ancestors. This result in a split in one's identity, identity is shifting, being forced to adapt and change towards a culture whose values are at odds with one's own. Yet there is little voice to challenge or question this, as no one listens and it feels as though no one cares

because the structures imposed reflect and are written by the world which is forcing one to adapt.

7.4 Embodied Interpretation of Vulnerability

Van Manen (2013) identified that phenomenological writing involves “not only our head and hand but our whole sensual and sentiment embodied being”. Indeed some of his critiques of a Giorgi approach are centred on the process of undertaking the research. As a consequence, he argues the focus on the phenomenon being explored is lost in the scientific endeavour (van Manen 2013), even going as far as saying that thesis’s utilising this approach are boring (van Manen 2013). In contrast, he argues that the aim of phenomenology is to help us understand our humanness...the humanness of our existence (van Manen 2013). It was really important to me when sharing the experiences of vulnerability of the Gypsies and Travellers that I did justice to their experiences. I wanted to ensure that the essence of vulnerability touched people; that the essence presented to them resonated with their own life-world experience. Van Manen (2013) argues that in the singularity or essence you have to sense the universal, not in the sense of the universal empirically, rather the singularity or essence of the human experience which resonates with others. Within the essence and constituents already presented I have paid attention to both the articulation of the structure and the texture in sharing their experiences reflecting both the art and science of phenomenology (Finlay 2009). However after undertaking the analysis of the data and identifying the essence of vulnerability I attended a two week study school with Max Van Manen and was exposed to a more interpretive way of viewing phenomenology. Learning more about van Manen’s perspective on phenomenology, part of me wished to express their experience in a way which focussed more on the art of phenomenology and less on the scientific aspects which are the predominate focus in Giorgi’s approach.

Galvin and Todres (2009b; 308) identify the embodied interpretation as a more poetic form of representation. In the process of identifying this, one goes back and forth between the written text and one’s own embodied sense of the meanings from the data to search for words which evocatively express what is being said. They have developed this approach by drawing upon the work of Gadamer and Gendlin whilst not losing the scientific structural aspects of Giorgi. The strengths of this approach are that it enables the written text to become alive, to touch those that

hear it, enabling both a logical dimension of the head as well as evoking a heartfelt dimension. Therefore a more embodied interpretation of the essence of vulnerability would be:

I am located in the world but I do not feel part of it. Instead I sit on the periphery both physically, socially and psychologically, hidden from view. People do not want to see me, nor do they accept who I am. Instead they want me to be different... but in being different, I am not me.

I feel trapped, I cannot live the life I wish to live, a life thousands before me have lived, yet I am told that this way of life is wrong, but I have no voice to challenge because no one wants to listen and no one hears.

I am vulnerable because I cannot be me, I cannot live my life as I would wish, instead I am dictated to by others, others who do not know me nor wish to understand me. I feel as though I have to beg to be allowed to do the things that are important to me, why should that be, I am human too.

I am dying, in the future there will be none of me, yet my death is slow and painful and I weep and grieve for the loss of the life I have known, that others will never see.

I have included it here, even though Halling (2002) acknowledges that approaching experiences from the poetic and innovative use of language can be risky, doubly so in a PhD thesis considering part of the assessment of a thesis is on its rigour. However I feel that presenting the essence in both ways complements the structural scientific analysis as it enables the sharing of their experiences of vulnerability to be presented to a wider audience. This was really important within this research as the discourse surrounding the Gypsies and Travellers is often negative, centred on the identification of difference by othering and dehumanising them as being worthless. In order for their words to be heard I felt there needed to be an alignment of them and us focussing upon aspects of shared humanity. I have shared the embodied essence with students, colleagues (work and at a conference) and supervisors. I observed in them the impact it had. It resonated and spoke to them, evoking an

emotional response, as such meeting the requirements of phenomenological writing identified by Van Manen. Likewise I have also shared the first essence (reflecting a balance between textural and structural) with colleagues and also noted the impact it has albeit differently as the embodied essence captures the heart whilst the first essence (reflecting both texture and structure) focus upon both the head and heart. Both articulate the emic perspective of vulnerability providing a very different discourse regarding Gypsies and Travellers and their experience of feeling vulnerable. It enables others to see our shared humanity and humanness which for me is the gift that phenomenological research brings.

This chapter presented the constituents and the essence of the lived experiences of vulnerability of Gypsies and Travellers when asked to “*tell me about stories/times in your life when your Gypsy/Traveller ways felt somehow challenged or threatened or not easy and what this meant to you*”. These essences have been presented in two ways, the first representing phenomenology as both a science and art and the second presenting a more creative embodied account of their vulnerability. When the constituents have been presented they are embedded with first person accounts demonstrating how the description has been formed by the evidence, a process that Ashworth (2000) refers to as descriptive adequacy congruent with the philosophy of descriptive phenomenology. This also provides the textural detail to assist the reader to understand something more about the Gypsy/Travellers’ embodied account of their vulnerability.

Chapter 8 Discussion

8.1 Introduction

This chapter starts by returning to the beginning of the research journey, identifying why the initial research was undertaken, as well as highlighting the study aims and objectives. It progresses with a reminder of the etic perspectives of vulnerability, examining what is currently understood in the academic literature about etic perspectives of vulnerability of a Gypsy/Travelling community. In doing so it also highlights where this study offers new insights or new understanding with regards to the external judgement of their vulnerability. The chapter progresses by presenting the unique contribution it offers by illuminating the previously hidden emic perspective of vulnerability of a Gypsy/Travelling community by presenting the main findings of this study. As each of these findings is presented, they are contextualised within what is already known from current research as well as critical commentary regarding what the thesis is adding to the wider evidence base. In doing so this thesis offer new perspectives both to the understanding of the concept of vulnerability itself as well as the understanding of vulnerability within a Gypsy /Travelling community.

This chapter argues that seeing the etic and emic perspectives of vulnerability as separate entities is limited and proposes a merging of both the external judgement and the lived experience into a new theoretical model of the Etemic perspective of vulnerability. It is this focus on the Etemic that will enable health and social care professionals to consider and develop services that are more culturally sensitive and therefore better placed to address the health and social inequalities faced by this particular community. This chapter also proposes how an understanding of this Etemic perspective of vulnerability can be used alongside the humanisation framework as a process to understand how individuals within the Gypsy/Travelling community can experience humanisation or dehumanisation. Taking this philosophy beyond that of viewing a service towards a way of exploring a community experience. Finally, the chapter recognises some of the limitations of this research as well as introducing some recommendations to academics, policy makers, practitioners, educators and finally the Gypsy/Traveller community themselves.

8.2 Research Aims and Objectives

Worldwide, there are more than 100 groups of Gypsies/Travellers, the numbers of which are estimated to be about 12 million people (Van Cleemput et al. 2007). Yet the Gypsy/Travelling community are often identified within the professional literature as a vulnerable group, due to poor health status (Goward et al. 2006; Parry et al. 2007), difficulties accessing services (Cemlyn 2000b) as well as their marginalised status within society (Van Cleemput et al. 2007; McCaffery 2009). Exploring this further in the literature review identified that the conceptualisation of Gypsies and Travellers as a vulnerable group largely focussed upon the etic (normative) perspective of their vulnerability (Spiers 2000) from an outsider perspective. However there was no exploration of the Gypsy/Traveller lived experience of vulnerability and as such their voice was missing in the academic discourse.

The aim of this research therefore was to understand something more about the experiences of vulnerability from a Gypsy/Traveller community perspective. Through conducting the literature review it was recognised that the term vulnerability is a somewhat nebulous term which is difficult to define. As such, this research had to explore the breadth of experiences associated with the term vulnerability from a Gypsy/Traveller perspective. Once this was identified, one facet of the experience of vulnerability was explored in depth (being part of a cultural group with threatened cultural identity and heritage), illuminating the essence of this dimension of the phenomenon. This study was successful in meeting its aims as it has solicited and shared the missing perspective (those of the community's itself) in understanding vulnerability of a Gypsy/Traveller community. Before discussing the findings of the lived experience (emic perspective) of vulnerability, it is really important to understand the context of why the lived experience is so important in public services.

8.3 Hearing People's Voices in Statutory Services

As identified within the literature review (chapter 2) there is an increasing priority within statutory services to ensure individual voices and experiences about care are heard (Department of Health 2005a; Social Care Institute for Excellence 2007; Department of Health 2009b, 2010), in order to ensure the services are responsive to patients/clients' needs. This movement towards valuing the lived experience has

evolved to the degree that patients’ stories and experiences are now being recognised as quality indicators (Care Quality Commission 2013) in both health and social care. Yet capturing the individual voice can be particularly challenging for services, especially with marginalised individuals and communities. Gypsies and Travellers are often identified as a hard to reach community (Greenfields and Home 2006) due to issues such as mistrust of the settled community and their transient lifestyle; as such little is known about their experiences. Exploring and presenting their lived experience of vulnerability contributes to this wider health and social care agenda of “nothing about me without me” (Department of Health 2010; 13) assisting services and individuals to develop their professional understanding of vulnerability experienced by this largely hidden community.

8.4 Etic Perspective of Vulnerability

The etic perspective of vulnerability relates to the “susceptibility to and possibility of harm” (Spiers 2000; 716). It was apparent whilst undertaking the thematic critical review of the existing literature (see chapter 2) that this was the predominant focus within the professional literature. From scoping this literature it led to the identification of a variety of differing theoretical perspectives of vulnerability (Figure 2).

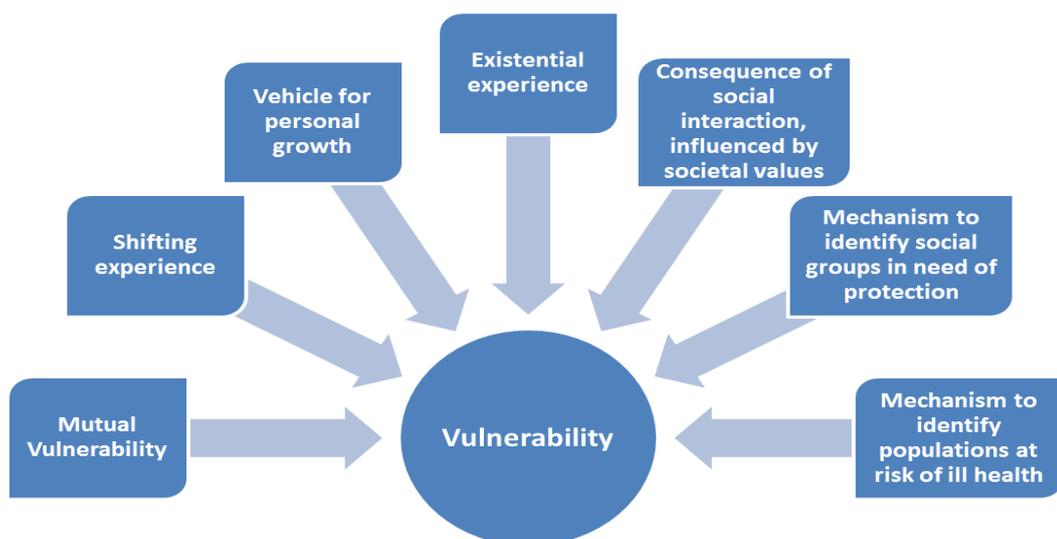


Figure 2 Differing Theoretical Perspectives of Vulnerability (Heaslip 2013a)

Exploring these theoretical (etic) perspectives of vulnerability within the context of the Gypsy/Travelling community it could be identified that the Gypsy/Travelling community are vulnerable due to:

- Mechanism to identify populations at risk of ill health - It is clearly evident from the evidence base that Gypsies and Travellers have a poorer physical and mental health (Goward et al. 2006; Parry et al. 2007) in comparison to the settled community. They are also much more likely to die prematurely (Parry et al. 2007).
- Mechanism to identify social groups in need of protection – Gypsies and Travellers are at risk of abuse within the context of statutory services due to the poor public perception of their community and issues related to institutionalised racism. It is clearly evident that they are at risk of receiving dehumanised, discriminatory care. In addition within the context of research Gypsies and Travellers would also be identified as vulnerable due to concerns re literacy in the community (Okely 1983; McCaffery 2009).
- Consequence of social interaction influenced by societal values – it is evident that Gypsies and Travellers are a highly marginalised community (Van Cleemput et al. 2007) who often experience discrimination and oppression (McCaffery 2009) and this can lead to inequity and inequality due to their poor social status within society (Heaslip 2013a).
- Shifting Experience – This perspective identifies vulnerability as a continuum and the transient, nomadic nature of the Gypsy/Traveller community increases this vulnerability as well as the current legislation which has largely criminalised nomadism (Greenfields 2007) leading to many Gypsy/Travellers becoming homeless.
- Existential Experience – under this theoretical perspective it can be argued that all human beings are vulnerable due to our social and biological constraints.
- Mutual Vulnerability – this theoretical perspective identified that nurses can also be vulnerable due to their professional role and interactions with patients (Heaslip and Board 2012). This can be perpetuated through a lack of cultural understanding regarding cultural practices of Gypsies and Travellers. For example, through the process of conducting this research I have had many nurses share that they have felt very uncomfortable and felt threatened at times when they have looked after a Gypsy/Traveller in hospital. They have spoken about feeling bombarded by the patient's family

as numerous family members visit which far exceeds the numbers permitted in local hospital policies. Yet when I have explained some of the cultural practices of a strong desire to look after their own and the importance of family they have been able to rationalise this and feel less threatened. This understanding of the nurses' vulnerability is important as it can lead to nurses disengaging with patients.

- Vehicle for Personal Growth – Little is written on this aspect of vulnerability as the etic perspective tends to focus upon vulnerability being associated with frailty, weakness and inferiority. This in itself is problematic as vulnerability then becomes associated with a negative label and can lead to disempowered, welfaristic practice. Yet feeling vulnerable can be positive, initiating new learning and new ways of being, leading to personal and professional growth (Stenbock-Hukt and Sarvimäki 2011).

Seeing vulnerability in the first three ways (mechanism to identify population at risk from ill health, mechanism to identify social groups at risk of harm and a consequence of social interaction) can lead to a reductionist perspective of vulnerability. Whilst it can be argued that this reductionist perspective is important as a mechanism to identify unmet clinical need it does little to explore why. For example, it enables the identification that Gypsies and Travellers experience poorer health in comparison to the settled community, however knowing this does not necessarily enable services to be developed which adequately address this unmet need. Without understanding how and why people experience vulnerability then how can practitioners and service managers ensure that the services being developed truly address the community's needs. Therefore it is important to appreciate and understand the lived emic experience of vulnerability in order to balance the reductionist alongside the humanist perspective of vulnerability.

8.5 Emic Perspective - What this study adds

It was clearly evident that the emic (lived experience) perspective of vulnerability (Spiers 2000) is largely silent within the academic discourse, even though a variety of individuals were defined as being vulnerable (older people, children, people with mental health needs, individuals with a disability, people who were homeless or living with an addiction as well as people from black and ethnic minority groups). This maybe reflects a wider societal discourse of professional knowledge being

privileged, whilst the individual story is of little importance in comparison. As such, this thesis largely entered uncharted territory by seeking to understand something more about this lived experience. The methods chosen to undertake this consisted of a two phase study (Todres and Galvin 2005; Heaslip 2011):

- Phase 1 – As vulnerability is not a single phenomenon but consists of several phenomena which are contextually defined. As a Gorgi (non Gypsy) I had limited knowledge and understanding regarding the multi-faceted experiences of vulnerability of individuals within the Gypsy/Travelling community. Therefore, Phase 1 included a breadth phase to enable an understanding of the significant phenomena of vulnerability that individuals within the Gypsy/Travelling community had lived through. This led to the development of a narrative identity of vulnerability experienced by individuals within the Gypsy/Traveller community.
- Phase 2 – Further developed this narrative identity of vulnerability by undertaking a depth study on one facet of vulnerability linked to being part of a cultural group with threatened cultural identity and heritage. This was undertaken using descriptive phenomenology.

Both the breadth and depth phases explored the lived experience of vulnerability and offers an insight to the experiences of vulnerability of Gypsies and Travellers. As such it presents something new towards our understanding of vulnerability more generally, and specifically our understanding of vulnerability of a Gypsy/Travelling community (see figure 5). In order to articulate the contribution this thesis makes the main findings from the study will be explored in turn with respect to the wider knowledge that is currently known regarding Gypsies and Travellers and identify the new insights this study offers.

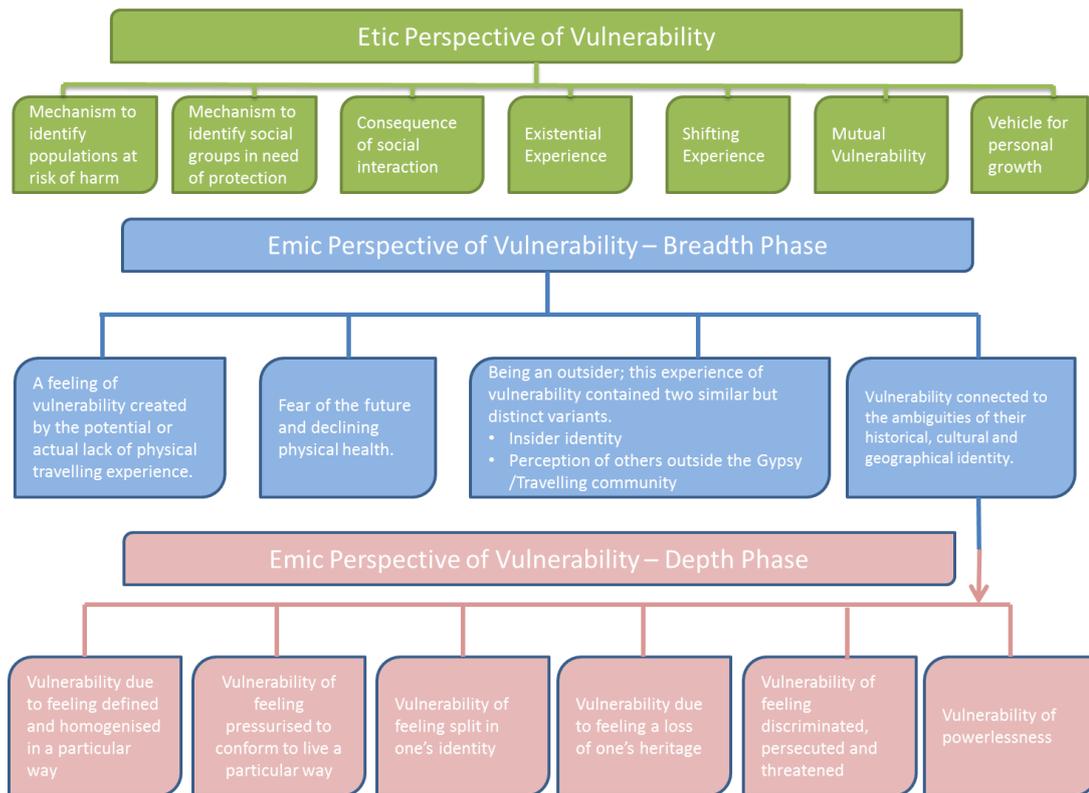


Figure 5 Findings of Breadth and Depth Phase

8.5.1 Phase 1

Phase one explored the breadth of experiences of vulnerability of Gypsies and Travellers. Four major facets of the phenomenon of vulnerability were identified (Figure 5):

- A feeling of vulnerability created by the potential or actual lack of physical travelling experience.
- Fear of the future and declining physical health.
- Being an outsider; this experience of vulnerability contained two similar but distinct variants.
 - Insider identity
 - Perception of others outside the Gypsy /Travelling community
- Vulnerability connected to the ambiguities of their historical, cultural and geographical identity.

8.5.1.1 A feeling of vulnerability created by the potential or actual lack of physical travelling experience

Participants felt vulnerable due to an inability to travel, because of legislative changes which restricted their ability to live on the open road. It was clearly evident there was a close embodiment with the natural earth, as such travelling was associated with feeling free both physically and psychologically. This psychological freedom was associated with the potential to travel, even if they were not physically nomadic at that point of time. The possibility of travel enabled a sense of freedom, and this has also been found by Cemlyn (2008). An ability to travel was directly associated with their perception of themselves as Gypsies and Travellers and integral to who they were. Therefore an inability to travel was met with sadness and grieving. In addition, travelling gave them a sense of space which was not provided on council sites, instead they felt forced to live in areas of poor quality away from nature. These insights are vital regarding long-term planning regarding both temporary and permanent site development. There are ongoing tensions regarding management of Gypsies and Travellers who are actively travelling. Currently there are very few temporary stopping sites which results in Gypsies and Travellers stopping on public land (such as parks, school fields, car parks etc.), these areas are not equipped for human habitation and therefore difficulties emerge with issue of human waste and conflicts arise between councils, police and Gypsies/Travellers regarding evictions. These are often highly publicised in local media and continue to fuel the negative discourse that surrounds Gypsies and Travellers furthering the othering and marginalisation of this community. Yet providing transient sites which enable Gypsies and Travellers to travel would address this as it would reduce the need for Gypsies and Travellers to stop on public land.

8.5.1.2 Fear of the future and declining physical health.

This facet identifies a sense of vulnerability related to declining physical health and fear of the future. From my clinical background it is evident that this facet is not isolated to individuals within the Gypsy/Travelling community but is also felt by those in the settled community. It is important to recognise that this is a shared human experience, and focussing upon these shared experiences can reduce othering. Here the participants spoke about accessing healthcare and some of the challenges it creates. This difficulty in accessing services by Gypsies and Travellers has also been identified by Cemlyn (2000b). However the majority of work focussed on Gypsies accessing healthcare has been within primary care (Dion 2007, 2008;

Francis 2009). Most notably in this thesis was the experience of hospitalisation which was challenging, in that not only was there a fear of germs related to their cultural perceptions of pollution and *mochadi* but also the environment of a hospital itself, as it was a direct contrast to their normal experiences of living. It is known that Gypsies/Travellers experience poorer health than the settled community (Parry et al. 2007) and as such will need to access such services. An awareness of this vulnerability due to fear of declining physical health could help practitioners have a better understanding of how they can optimise working with individual Gypsy and Travellers. Gypsies and Travellers will access healthcare services at a much later stage of the illness trajectory (see section 2.4) preferring to access traditional herbal remedies first. Where possible healthcare should be provided enabling individual Gypsies and Travellers to remain in their own home due to concerns related to hospitals being places of gorgi pollution (Okely 1983). If Gypsies and Travellers have to be admitted to a hospital setting then it is vitally important that their cultural values are respected. For example, simple strategies can be implemented such as ensuring:

- Two flannels and bars of soap are provided to maintain the separation between purity (*wuzho*) and pollution (*marimé*) (Vivian and Dundes 2004).
- Family members are facilitated to stay perhaps by locating the individual to a side room or identifying a room for the family to wait. As research by Wetzel (1983) and Jesper (2008) highlight the importance of family to the Gypsy/Travelling culture, this is even more important during times of illness and separation from the community.
- Recognising and respecting the cultural sexual taboos (Wetzel et al. 1983) by ensuring that female Gypsies and Travellers are not looked after by male members of staff (especially if it is gynaecological issue) or that male staff members are chaperoned so female Gypsy/Travellers are not left alone with them.
- The individual is located next to a window with a view of nature, which would ease their comfort during their stay.
- Ongoing reassurance and recognition that literacy can be poor and therefore the importance of spending time reassuring the individual regarding what is happening is paramount.

Participants also identified feeling vulnerable due to a concern for the future, and a time in which they are no longer able to stay within their own homes. Again this is an experience that could resonate with people outside of the Gypsy/Traveller community. Yet for Gypsies and Travellers this is particularly relevant. Traditionally the community would look after its elder generation, however due to increased marriages between Gypsies/Travellers and the settled community there are concerns regarding whether the practice of looking after ones' elderly may also be lost. Concerns then relate to requiring long-term residential care and this relates to moving into a building where none of your cultural values are present.

8.5.1.3 Being an outsider; this experience of vulnerability contained two similar but distinct variants of insider identity and Perception of Others outside the Gypsy/Traveller Community

Another facet of vulnerability identified in the Phase one breadth phase related to the negative perceptions of Gypsies and Travellers from people outside the community. This links to the previous facet in which there are limited stopping areas for Gypsies and Travellers forcing them to stop on public spaces. As such, there is a very negative discourse surrounding Gypsies and Travellers and they are associated with criminality, waste, destructive and anti-social behaviour. These negative perceptions of Gypsies/Travellers have led them to withdraw from wider society and stay within their own community. It was evident in this facet, that they experienced feeling vulnerable when they were interacting with others outside their community but not when they were interacting with others within their own community. Almost as if being with one's own people was a safety blanket that provided comfort and reassurance. Research by Smith and Ruston (2013) found similar results. Their study of thirty nine interviews with Gypsies and Travellers identified a theme of Networks; Proximity and Health in which they highlighted the role that social relations play in maintaining well-being and a collective resistance to social isolation. Yet this study takes this awareness further, highlighting negative attitudes towards Gypsies and Travellers from the outside community perpetuates this drive to staying within one's own. This awareness has huge practice implications for statutory services as they need to recognise that locating a Gypsy/Traveller on their own without support from their peers increases social isolation and social tension. For example in a hospital context, anecdotal evidence highlights that when a member from the Gypsy/Travelling family is admitted often large numbers of the community will go to visit and this in the past has caused

tension with regards to visiting numbers and times. Yet this study enables understanding of why this occurs and can lead to services being adapted to enable this ongoing cultural support. Similarly, in an education context it is important to locate Gypsy/Traveller children together.

8.5.1.4 Vulnerability connected to the ambiguities of their historical, cultural and geographical identity.

Here the participants spoke about some of the ambiguities of their identity, highlighting that people outside the Gypsy/Travelling community do not fully appreciate the cultural aspect of their lives. Instead perceiving they were only Gypsies and Travellers if they lived in a wagon on the road, rather than appreciating that some Gypsies/Travellers lived in housing and some in wagons in permanent sites. This perception was also made explicit to me when presenting some of the findings from Phase one to a local council, as I was approached by a counsellor who admitted afterwards he previously did not understand how they were referred to as Gypsies and Travellers if they did not travel. This highlights a lack of cultural understanding and recognition of Gypsies and Travellers as a distinct cultural group and is perhaps unsurprising as it was only in the 2011 census that they were added as a distinct ethnic group following recognition under the Equality Act 2010.

It was evident that many participants associated a strength associated with their cultural identity and was identified in the previous facet. However, there was also recognition that this cultural identity was changing due to increased integration with Gorgis through marriage and increased work opportunities for Gypsies and Travellers. Working patterns were also changing, with a move away from traditional practices of working in agriculture due to increased industrialisation on farms. As well as a move away from rearing and selling horses due to their reduction within farming practice.

Lastly, there was a sense from all of the participants in Phase 1 that their way of life and their culture was being eradicated and eroded, with the participants making stark predications regarding the future. They expressed that they felt forced to adapt to a more settled existence which they felt was at odds with their cultural identify, comparing this with the genocide that occurred in the Holocaust. It seemed as if there was a particular kind of vulnerability prevalent in Gypsies and Travellers in

today's society which was the experience of being part of a cultural group with threatened cultural identity and heritage and this was the phenomenon that was explored further in Phase2.

8.5.2 Phase 2

Phase 2 consisted of the depth phase (figure 3) in which further interviews occurred, exploring with participants times in their lives when their Gypsy/Travellers ways felt somehow challenged or threatened or not easy. These interviews were analysed using descriptive phenomenology. From this six constituents of vulnerability were identified including:

- Vulnerability due to feeling defined and homogenised in a particular way
- Vulnerability of feeling pressurised to conform to live a particular way
- Vulnerability of feeling split in one's identity
- Vulnerability due to feeling a loss of one's heritage
- Vulnerability of feeling discriminated, persecuted and threatened
- Vulnerability of powerlessness

These constituents were under a single structure or essence, which was also presented. This thesis presented this essence in two ways firstly following the traditional approach as directed by Giorgi (1997) and secondly an embodied interpretation advocated by Galvin and Todres (2009b). This embodied interpretation was inspired by Van Manen (2013) as there was a desire to ensure the thesis touched and presented the humanness of the phenomenon of vulnerability. The constituents and essence provide a very different discourse to the etic perspective of vulnerability that was identified and presented in the literature review (Chapter 2). The etic perspective of vulnerability identified differing ways in which vulnerability can be used to categorise individuals or groups. In contrast, the constituents and essence present ways in which vulnerability is existentially. In order to explore this in more depth, each constituent is presented in turn, exploring the new insights it offers in developing an understanding of vulnerability of individuals within the Gypsy/Travelling community.

8.5.2.1 Vulnerability due to feeling defined and homogenised in a particular way

It was clearly evident that the participants felt homogenised, and categorised together rather than being seen as distinct, separate cultural groups. This process of homogenisation of Showman, Irish Travellers, Romany, English Gypsies and English Travellers does little to appreciate the differences between these cultures and as such can lead to stereotypical practices. This process of grouping whilst a natural human way of coding and storing information (Ryden 2013) can lead to difficulties, especially with regards to stereotyping in which all members of a given community are assigned similar attributes, often negative in nature. This was evident within this study as many participants recalled accounts in which they themselves or their community were identified as thieves, reflective of a wider societal discourse of Gypsies and Travellers as being deceitful, untrustworthy and dishonest. An extract from the findings of Phase 1 reflects this:

Tommy, a Showman, expressed that Gypsies and Travellers are perceived as thieves recalling an interaction with a farmer who said *“I’ve caught you. I’ve had enough of your sort...bloody robbing me or this and that”*.

The difficulties associated with this labelling can be explored using labelling theory, which reflects the powerbase within society, in which the majority (settled community) designate the negative label to the minority (Gypsies/Travellers), in this case Gypsies/Travellers being thieves. Becker (1963) demonstrated that these deviant identities occur not through the actions themselves but the labels associated with them, thus we see what it is we wish to see. This is apparent when examining the over-representation of Travellers in prison even though Cemlyn et al. (2009) identifies there are similar levels of criminal activity between the settled and Gypsy/Traveller communities. This was highlighted in this study as many participants identified that Gypsies and Travellers were automatically accused or blamed for any theft that occurred. This can lead to the development of a self-fulfilling prophecy, or master status (Lemert 1972) in which the deviant behaviour becomes central to one’s conception of themselves. This is really important when considering the younger generation of the community who perceive to be “damned if they do and damned if they don’t”. This self-fulfilling prophecy could potentially lead to an increase in deviant behaviour of the Gypsy/Travelling community.

This study also highlights that accusations of negative behaviour also leads to resentment and ill feeling between the two communities, as is apparent in the case of Tommy (Phase 1):

“Coming from the travelling community, I don’t feel connected to the settled community at all”.

They don’t like the settled community and the settled community don’t like the Travellers. There’s a lot of Travellers they’re sick to death of the way they’ve been treated so they’ve called an all-out war against the settled people – Tommy.

This has huge implications for practice, most notably the potential for health and social care professionals who may respond to focussing upon a homogenised negative label rather than the person leading to poor quality care as well as further perpetuating the divide between the settled and Gypsy/Traveller community.

8.5.2.2 Vulnerability of feeling pressurised to conform to live a particular way

It was evident from speaking to the participants that they feel under pressure to conform to living a particular way which is incongruent with the way they would wish to live. Using the example of education, it was evident that there was a discord regarding the perspective and value of formal compulsory education between the two communities. Within the settled community, there is a large focus on academic achievement, largely fuelled by changes in the educational system such as national testing at key stages. However this research identified that this focus on academic achievement was not as important within the Gypsy/Traveller community. Instead more priority was placed on informal work-based education; working alongside parents earning a trade which would eventually provide financial support to your family. This focus on work-based informal education was also found in a study by Convery and O’Brien (2012).

Whilst school education was deemed important, especially the ability to read and write, it was felt that this often occurred at the expense of their Gypsy/Traveller culture. For example, many of the participants whilst they valued schooling of their

children they also wanted the right to remove their children from school to enable them to go off travelling. This is a tension especially considering the wider concerns regarding education and Gypsy/Traveller children. Lepper (2012) identified that only 12% of Gypsy/Traveller children left secondary school with five or more GCSE's grade A* to C, in comparison to 58.2% of the settled population. In addition to this, it is estimated that Gypsy/Traveller children are two key stages behind their counterparts (LeedsGate 2014). As such there is a greater focus on Gypsy/Traveller children's education within statutory services; the Department for Education and Skills (2003) identify that Gypsy/Traveller children over six years of age have to attend at least two hundred half day sessions. This can be explained using the sociological theory of isomorphic converges (Beckert 2010), in which the pursuit of legitimacy in society pushes organisations to behave in certain ways leading to homogenised expectations. Academic achievement is a powerful influence on schools as they are judged on the percentage of its pupils achieving grades A-C in GCSE. This in turn dictates local policies and procedures regarding the focus of education being on academic achievement. It was clear from this research that this leads to difficulties for Gypsy/Traveller children as they do not necessarily value academic achievement in the same way. Beckert (2010) identifies that the problems associated with isomorphic converges is often due to the cultural clashes. This results in schools managing attendance figures more rigorously, in order to increase academic output from Gypsy/Traveller children. These restrictions were keenly felt by the participants who felt that these restrictions negatively impacted upon their cultural belief and values with respect to travelling as they would experience penalties from education welfare services. It was evident that there is a cultural dissonance as the majority of the participants spoken to did not have aspirations for themselves or their children to go to university, indeed for the participants who did do this it was perceived with a degree of suspicion by their own community, and these individuals were challenged about becoming "Gorgified".

Another factor contributing to a lack of formal education within the community was linked to issue of bullying within schools. This was more problematic within secondary schools, and correlated with the age in which difficulties with attendance started to occur. Numerous participants in this research had either experienced or witnessed bullying within schools and this corresponds with national evidence also reflecting this trend (Department for Education and Skills 2003; Lepper 2012; LeedsGate 2014), which can lead to young people leaving education early. Where

the participants had experienced bullying their perception was that little was done within the school to address it, and this links to wider societal perceptions regarding discrimination, persecution and oppression (which shall be discussed later in this chapter). Ultimately there is a need for anti-bullying strategies to be implemented within schools (Cemlyn et al. 2009) to address ongoing issues related to racial bullying.

Shubin and Swanson (2010) argue that nomadic ways are often entangled within power relations, and this appears to be true for Gypsies and Travellers as highlighted above. In both Phase 1 and Phase 2 of this study participants expressed difficulties in remaining nomadic and being able to travel, which they felt was increasingly being denied to them due to the increasing legislation which prohibited travelling (Okely 2011). Yet this research identified that an ability to travel is a central tenant of Gypsy/Traveller culture and at the heart of their self-identity, findings that have also been identified by Shubin and Swanson (2010) and Van Cleemput (2007) whose participants also linked the ability to travel to a sense of freedom and choice, yet their participants also recognised that this lifestyle was increasingly being denied to them which in turn was increasing their feelings of vulnerability. During the process of undertaking this research and sharing some of the findings at various points with students, academic colleagues as well as with local counsellors, questions would often be posed regarding how Gypsies and Travellers still perceived themselves as Travellers when the majority of them could not or did not actually travel. This reflects a lack of understanding of the cultural history and values associated with being Gypsy/Traveller. Convery and O'Brien (2012) agrees that Gypsies do not need to travel in order to be identified as Gypsies and being a Gypsy is about shared cultural values. As such Shubin and Swanson (2010) refer to travelling as the "spirit of travel". It is clear in this study that the majority of the participants desired an ability to be able to travel, to live a lifestyle in which thousands of generations had before them. Travelling within Gypsy/Traveller culture is not just about a sense of being free, nor about whom they are but it is also fundamental with regards to community cohesion. Due to restrictions on travelling the ability to meet with extended family members are much more problematic. This research identified that even Gypsy/Travellers who own their own plot of land and have planning permission to live on there often find restrictions placed upon them regarding additional caravans on the site, which can reduce opportunities for family

to visit, even though a sense of family is fundamental to their culture and identity as a Gypsy/Traveller.

For other participants who live on a council maintained site, there are concerns regarding these sites losing their identity as Gypsy/Travellers sites and are becoming more like holiday parks. This is related to restrictions being placed upon the residents living there, such as an inability to have horses or silkies on the site and this is having a negative impact upon their feeling of 'being at home', increasing their sense of vulnerability. Tremlett (2009) identifies that Roma minorities often cite home as the central heart of their and the reproduction of the Gypsy Way. Place is far greater than a physical locality, Convey and O'Brien (2012; p333) argues that a sense of place "mediates our relationship with the world and with each other". They also acknowledge kinship place as a geographical place for kinship activities which are fundamental for identity and sense of place. This for Gypsies and Travellers is imperative, and as such it is vital that redevelopments of council sites do not restrict activities which facilitate this kinship space, such as ability to cook on an open fire, to come together to tell stories and having silkies and horses on the site.

As identified in the findings sections (chapter 7) many Gypsies and Travellers responded to this pressure to conform to live a certain way, by living inauthentically. Wood et al. (2008; P386) defines authentic living as:

"Behaving and expressing emotions in such a way that is consistent with the conscious awareness of physiological states, emotions, beliefs and cognitions. In other words authentic living involves being true to oneself in most situations and living in accordance with one's values and beliefs".

It is evident that in this study the majority of the participants were living inauthentically. They were expected to conform to living a sedentary lifestyle due to restrictions placed upon them with regards to travelling. Yet they were also denied other important cultural aspects, such as an ability to come together as a community over an open fire, to tell stories and to cook in the way in which countless of their previous generations had. Further restrictions governing the way in which they educated their young were also incongruent regarding their values of education. Wood et al. developed an authenticity scale (2008) and from this identified that where there is this mismatch it can result in self-alienation, in which one lacks a

sense of identity through the subjective feeling of not knowing oneself. These feelings of self-alienation reflect inauthenticity (Pinto et al. 2012). Guignon (2004) argues that authenticity is not only related to what we believe and feel, but more importantly it is about being able to honestly express those beliefs and feelings. Therefore authenticity is far greater than just at a personal level but also influenced at a social and societal level. As such, inauthenticity involves worrying about fitting in and being a well-adapted member of society. Guignon (2004; 162) further argues that one can only feel authentic in a “world which recognises individual talents, respects differences, provides equal opportunity, acknowledges the value of criticism and unpopular ideas and ensure there are no obstacles to freedom of expression”. From viewing authentically in this way, it could be argued that Gypsy/Travellers are trying to live authentically but in an inauthentic world. It is the world in which they live that forces the inauthenticity. For example if you consider the participants’ responses towards the inability to have a fire is to simply have a fire when the wardens are away, so it could be questioned whether this act of resisting rebellion perhaps is their living authentically in a world which does not permit it. There is a resonance of these findings of being forced to live inauthentically due to a wider societal pressure to conform to living a certain way with other indigenous groups such as Aborigines in Australia (Delauney 2013), First Nations, Inuit and Metis in Canada (Shantz 2010), Adivasis in Bangladesh (Khan and Samadder 2012) and Kuy in Cambodia (Swift 2013), all of which have been forced to adapt to living a way at odds with their own cultural identity.

There are long-term implications of living inauthentically. Authenticity is identified by (Wright 2008) as a corner-stone of mental health as it is linked to self-esteem and coping skills which contribute to an individual’s psychological well-being. Research by Satici et al. (2013) identifies a correlation between inauthenticity and psychological vulnerability. This is interesting, considering the evidence from the emic perspective of vulnerability of Gypsies and Travellers identifies that mental health is poorer in Gypsy/Travelling communities (Parry et al. 2007) as well as other indigenous groups (Shantz 2010; Delauney 2013) and this study can assist in exploring why, through the appreciation of the difficulties the communities face with both self and societal inauthenticity.

8.5.2.3 Vulnerability of feeling split in one's identity and response of complexifying one's identity

It is evident in the findings of this study that the identity an individual may hold as a Gypsy/Traveller is changing. One of the constituents of vulnerability was linked to feeling split in one's identity and this is occurring due to closer integration between Gypsy/Traveller and the settled community leading to greater opportunities for individuals. This split in identity was also compounded by the pressure to conform to live a certain way in which external influences were impacting upon Gypsy/Traveller lives. It was clear that many of the individuals felt pressured to change the way in which they lived, to lose identity as Gypsies and Travellers and to become more settled. This assimilation to Gorgi culture was also identified in a study by Van Cleemput et al. (2007) whose participants perceived they were being socially assimilated into Gorgi lifestyle which was a threat to both their identity and culture as Gypsies/Travellers. This changing identity for Gypsies/Travellers is not just located within the UK. A study by Zsuzsa (2012) in Romania also identified key similar themes of changes in identity resulting in multiple identities due to a merging of their traditional cultural identities with a new identity emerging due to contemporary society. This thesis found similar results to Zsuzsa's study identifying that this embracing the new, whilst not losing the old was what led to the development of complexifying one's identity. Yet this thesis identified aspects that were not recognised in Zsuzsa's study, such as this being more problematic for younger women in the community, who at times expressed feeling torn in two. Convery and O'Brien's (2012) study recognise that family networks and social relationships within Gypsy/Traveller communities help to preserve self-identity during change. However, this thesis recognises that this family network and social relationships can also compound this fracturing of identity as the participants were challenged by their own community, being accused of becoming more "Gorgified" and therefore had to consciously be aware of managing the expectations of both communities.

This complexifying one's identity as a Gypsy/Traveller is also influenced by the wider perceptions and attitudes towards Gypsies and Travellers. Within this study different terms were used to describe themselves as Gypsies. Some of the participants identified themselves as Romany whereas others used the term English Traveller. This may have been in part a defence towards the negative public perceptions of the migration of Eastern European Roma to the UK and the wish to

identify themselves as British born to distinguish themselves from other Gypsy/Travellers. At other times, participants within the study chose to hide their status as Gypsies and Travellers for fear of discrimination and persecution. These findings are similar to those by Convery and O'Brien (2012) whose study identified that the stigma associated with the term Gypsy in European society is one of the reasons why some individuals are reluctant to share their identity. In this study this led to some individuals having to lead a double identity of personal internal Gypsy identity and public external identity in which their status as Gypsy/Traveller status is not acknowledged.

The perception we have of ourselves and our lives is learned through the process of habitus. Bourdieu (Maton 2012; 50) defines habitus as “a property of actors (whether individuals, groups or institutions) that comprises a structured and structuring structure”. Habitus is structured by our past and present circumstances such as family upbringing and educational experiences which in turn influence the way in which we view the world and opportunities within it. As such it is also structuring, in that these perceptions shape our practice and our behaviour. Lastly, it is a structure in that it is systematically ordered rather than random or patterned. As such habitus focusses on ways of acting, feeling, thinking and being, capturing our history into the present day which influences our choices to act in certain ways. As individuals we are socialised into habitus through our families who pass on values, beliefs and attitudes about the world in which we live. It is apparent that the habitus that is passed on to younger members of the Gypsy/Traveller community is a sense of mistrust towards the settled community, of a fear of being treated differently which is often reinforced through early interactions with those outside the Gypsy/Traveller culture which perpetuate the lack of understanding and trust between the two communities. This leads to Gypsy/Travellers choosing to self-segregate (as identified in Phase 1) as a mechanism of coping with the feelings of hostility from the settled community. This in turn does little to redress the lack of understanding between the two communities and further perpetuates stereotypical, homogenised views.

8.5.2.4 Vulnerability of feeling discriminated, persecuted and threatened, associated response of hiding and Vulnerability of Powerlessness

It is clear from the study that all of the participants identified that they felt discriminated, persecuted and threatened and this manifested in numerous ways. For one participant this occurred through a major physical threat, of having his post box shot at with twelve air rifle pellets; this was very distressing for him as he has his grandchildren living on the site and he was obviously concerned for their safety. Other example of physical violence experienced by participants related to having stones and eggs thrown at their caravan, clearly providing a message to them that they are not welcome and not wanted by the wider community in which they live. For others the discrimination was psychological, being called names and negative comments being made. One participant was offered £30,000 to leave the village where she had spent significant parts of her life. This psychological discrimination and persecution occurred at both a covert and overt way. Overtly, participants were refused entry into pubs and clubs simply on the basis of their cultural identity and covertly in which the individuals found themselves being followed around in their local shop every time they went shopping by security guards. This discrimination was identified in both Phase 1 (breadth) and Phase 2 (depth) aspects of this study and by all of the participants. This discrimination experienced by Gypsies and Travellers in this research is not an isolated example; Cemlyn et al. (2009) identified that racism against Gypsy/Travellers is still common, and research by Smith and Rushton (2013) identified that Gypsies and Travellers were subject to a range of discriminatory practices because of their ethnic status. Indeed repeated opinion polls show that Gypsy/Travellers are the least liked minority group (Kabachnik 2009) and this research clearly identifies that discrimination against Gypsy/Travellers is still an ongoing issue.

It was evident that whilst some of the participants stated this discrimination did not bother them, many of them responded to it by reducing their levels of social engagement within the wider community, preferring to stay with their own families and on their own sites. This can perpetuate this sense of not belonging within the wider social community as well as perpetuating their experience of a split identity. Theodosiou (2003) utilised Probyn's perception of be-longing, including an affective dimension, seeing belonging as both being and longing. Using this perspective it is clear that Gypsies and Travellers can *be* in the world but do not necessarily find themselves *belonging* in it, they are not accepted for who they are, and this results

in the response of hiding one's identity through fear of persecution. This response of hiding is not just isolated to Gypsies/Travellers living in the UK. Grönfors (1982) and Okely (1983) identified this as a European phenomenon, highlighting that centuries of oppression throughout Europe has led to Gypsies/Travellers becoming as obscure as possible in order to survive. This sense of wishing to be with one's own kind has wider implications in that it can lead to self-segregation (as identified in Phase 1 of the study). It does lead to a wider sense of mistrust between the two communities and an open sense of hostility. This sense of mistrust between the two communities was also found in a study by Van Cleemput et al. (2007) which identified that Gypsies/Travellers perceived they were living in a hostile society, and had been for generations which perpetuated a lack of trust of the settled community. This lack of trust was also met with a sense of powerlessness for the future which leads to them feeling vulnerable. It is known that vulnerability is linked to control, in that the more control we feel we have then the less vulnerable we will feel and vice versa (Heaslip 2013b). As such feeling out of control to challenge this oppression can lead to feeling vulnerable.

This experience of feeling discriminated and persecuted is inextricably linked with racism. Yet it is almost seen as acceptable within society to be racist towards Gypsies and Travellers (Cemlyn et al. 2009; Smith and Ruston 2013). The participants in this study identified that the racist behaviour towards them as Gypsies and Travellers would not be tolerated against any other racial group. Chakraborti (2010) acknowledges that racism can be subtle and covert which leads to difficulties in individuals feeling able to report it. In a study Chakraborti (2010) undertook research with young black men and they identified similar examples to the participants of this study of being followed around in a shop, being made to feel as though their presence was not wanted or welcomed, which resulted in the participants reporting higher levels of anxiety. The experiences of Gypsies and Travellers is made more problematic as their skin tone is the same as the settled community and as such people may not equate their behaviour towards a fellow white person as racist (Chakraborti 2010). Research by Smith and Ruston's study (2013) with thirty-nine Gypsies and Travellers identified that participants expressed feeling of anxiety when located in bricks and mortar housing away from their community. However this research identified that this anxiety occurs, not just for those Gypsies and Travellers located in housing, but also during encounters in their local communities due to direct discrimination experienced as well as the fear of discrimination. It is known that Gypsies/Travellers are three times more likely to

have anxiety, and more than twice as likely to be depressed (Parry et al. 2007), perhaps the findings of this study can help to explain this.

However discrimination against Gypsies and Travellers is illegal since their identification as an ethnic minority under the Equality Act. A definition of a hate crime adapted by the Criminal Justice Agencies in 2007 (Department for Communities and Local Government 2012; Government. 2012) “any criminal offence which is perceived by the victim or any other persons, to be motivated by hostility or prejudice based on a person’s race or perceived race. Included subjects are: any racial group or ethnic background including countries within the United Kingdom and Gypsy and Traveller Groups”. Whilst this research did not specifically explore experiences of Gypsies and Travellers liaison with statutory services – it did highlight poor practice with regards to education, health, and the law.

Institutionalised racism within statutory services has been highlighted within the public domain previously due to high profile cases such as Stephen Lawrence (Macpherson 1999) and Blofeld Report (2003). This study identified that participants had witnessed or experienced othering and racism in healthcare services. These findings are supported by other studies which identified that discrimination by healthcare practitioners is a key factor in the poor utilisation of health services by Gypsies and Travellers (Cemlyn et al. 2009; Smith and Ruston 2013). This has huge professional implications; there is evidence that patients that are designated “unpopular” experience poorer quality of care (Stockwell 1972; Johnson and Webb 1995). Furthermore Gypsies and Travellers have the poorest health status in Britain, as well as a lower life expectancy than their settled counterparts (Smith and Ruston 2013). Therefore it can be argued they are a community which fundamentally requires access and support from health services. There is, to date, little research conducted exploring perceptions of healthcare staff regarding Gypsies and Travellers and this is required to examine the extent to which these practitioners’ practice may be influenced by the wider societal attitudes.

Research by Dion (2007) which explored perceptions of health of Gypsies and Travellers, concluded there is a need for better cultural awareness on the part of service providers in order to address the health needs of the Gypsy/Travelling community. The Equality and Human Rights Commission (2009) identify that the

Department of Health needs to develop guidance and training for health authorities and practitioners regarding Gypsies and Travellers. However Smith and Ruston (2013) identify that Gypsies and Travellers under-utilise healthcare, are an extremely hard to reach group due to their mistrust of the settled community, as such there is limited understanding of this community. This thesis can support this advocated training and guidance for practitioners and services as it offers a huge insight into their lived experience of vulnerability.

8.5.2.5 Vulnerability of powerlessness and response of resigning

Symbolic power according to Bourdieu relates to how social hierarchy can perpetuate social inequality (Schubert 2012). Equating this to Gypsies and Travellers, their lack of voice at a political or national level, results in their issues not being debated or addressed in a fair, transparent way. In contrast symbolic violence is the experience of feeling out of place, anxious, awkward, shamed and stupid (Samuel 2013; p402). Symbolic violence is often a mechanism in which marginalisation occurs (Hall 2004; p45). In its most simplest form marginalisation is the identification of difference (us and them) through othering (Maccallum 2002). In this, the other is often designated as having less value, less importance than we assign ourselves. Schwalbe et al. (2000) identifies three types of othering:

- 1) Oppressive othering – when one group seeks advantage by defining another group as morally and or intellectually inferior. This typically sees the overt or subtle assertion of difference as a deficit.
- 2) Implicit othering by the creation of powerful virtual selves – in the perception of identity – we see ourselves as powerful, worthy selves – therefore for anyone not like us must therefore be un-powerful or unworthy. In this case we surround ourselves with powerful others thus leading to an unequal distribution of wealth and power.
- 3) Defensive othering among subordinates – done by those seeking membership in the dominant group or to deflect stigma they experience as being part of the subordinate group.

These enter in a vicious cycle, those with symbolic power increase their power and those who are marginalised through the process of symbolic violence may find themselves becoming more marginalised. Taking the above example of a lack of a voice at a political level, many Gypsies and Travellers have found that their lives

have been fundamentally changed by politicians and yet, not only have they had little representation or voice, they also probably have little knowledge of these debates occurring, and if they did they may have a lack of the necessary resources to challenge. This is further apparent in day-to-day existence, Gypsies/Travellers live in a society, in which the majority do not share nor value their culture or community, therefore they are exposed to daily persecution and discrimination (Symbolic violence) but to whom will they challenge this behaviour of others. This violence can occur at a physical level but more than likely will manifest at a psychological level through the process of stereotyping and othering. They can raise these concerns with the police (however they have experienced racism and discrimination at the hands of the police) who can use policies and procedures to their own advantage (symbolic power). Another example is with regards to planning applications and the process by which a nomadic lifestyle has become criminalised by the process of symbolic power. This results in individuals becoming or feeling powerless to challenge and question the behaviour of others and this was clearly evident in this study.

This study offers insight into the experiences of othering by a Gypsy/Travelling community as all three examples of othering are apparent within this study. Individuals clearly experienced occasions in which they were blamed for actions without cause (oppressive othering) through the process of homogenization and not seeing the individual. Secondly, legislation and policies pressurizing Gypsy/Travellers to conform to living a particular way is an example of implicit othering, in which the settled community feels as though their way of living is the only way. This has resulted in defensive othering in which some participants in this study have blamed other Gypsies/Travellers for actions and have tried to distinguish themselves as not being Gypsies or Travellers by hiding who they are. Through the process of symbolic violence the vulnerability that Gypsies/Travellers feel is continually perpetuated, entering them into a cycle of vulnerability in which they feel oppressed but have no voice to challenge their oppressors.

8.5.2.6 Vulnerability due to feeling a loss of one's heritage and associated responses of mourning and resisting rebellion

Giddens (1991) argues that to be ontologically secure one needs to possess the answers to fundamental existential questions such as time, space, continuity and identity. He further argues that ontological security develops through childhood, as

the child learns to distinguish itself as separate from the world and in doing so creates a sense of being which is further nurtured through routines and consistency. Yet questions arise as to how an individual from the Gypsy/Travelling community develops this sense of security when their world is forever changing, leading to shifting identities and they are perpetually being moved and shifted both physically and psychologically. Perhaps this lack of ontological security in part helps to explain the sense of anxiety and sense of non-belonging previously identified. One of the most powerful aspects of this study was a sense that the individuals perceived their way of life was under threat by those in the settled community, that they were being eradicated. These findings have also been identified in studies on other indigenous groups who have also identified a feeling of being made to forcibly adapt their traditional cultural heritage in light of wider societal norms (Khan and Samadder 2012; Swift 2013) . These other indigenous groups going through enforced cultural change have similar poor health outcomes to Gypsies/Travellers in terms of higher physical and mental illness in comparison to the wider settled population (Shantz 2010; Delauney 2013).

8.5.2.7 Essence of vulnerability

The essence articulates the whole of the phenomenon of vulnerability of which the constituents play just a part. It highlights the totality of the human experience of vulnerability which previously has been compartmentalised. Yet methodologically, it does this in a way that transcends the negative label of Gypsies and Travellers and focusses upon what unites us as human beings – our shared humanity. Highlighting the desperation of their existence, of having a past but no present and no future, as well as clearly expressing in human terms what it feels like to be ostracised and not accepted. Presenting the findings in this way hopefully evokes a more empathetic response towards Gypsies and Travellers, as Sanghellini and Rosfort (2013) highlight that empathy develops when individuals perceive the universal humanity of another person's ordeal. Undertaking this study in this way truly privileges the voice of the community, yet presents their voice in a way which hopefully challenges the principal discourse surrounding Gypsies and Travellers and their vulnerability.

Exploring the emic perspective of vulnerability offers a richer, broader definition and perspective of vulnerability. Whilst the etic perspective of vulnerability was associated with words that do something to another, such as wounding and harm, the emic in contrast for Gypsies and Travellers is more linked with an internal and existential experience, such as suffering and a lack of freedom, to be who I was meant to be. This focus on the existential experience enables the transcendence of

the experiences of vulnerability beyond that of Gypsies and Travellers to other individuals and groups in society. Thus, the thesis contributes to the theoretical knowledge of vulnerability as a concept.

8.6 The Etemic Perspective

To date this chapter has explored what this research adds to what was already known regarding the etic perspective of vulnerability of Gypsies and Travellers. It provides an insight into the previously unknown and invisible emic perspective of vulnerability, expanding upon the previous work of Spiers (2000). However in exploring vulnerability, there are limitations to perceiving it either from an etic or emic perspective. In professional literature, there has been an over-reliance on examining and identifying vulnerable populations or groups (focussing upon the etic) and yet in doing so valuable information regarding the lived experience (emic) is missed. In contrast, exclusively focussing upon the emic experience of vulnerability could limit understanding of the wider community vulnerability. Therefore we can only truly understand vulnerability through a fusion between both the etic and emic perspectives. Therefore I would like to propose a new perspective which I refer to as the Etemic (figure 6). As can be seen from figure 6, the etic and emic perspective need to be perceived not as separate components but a yin yang, in which both together are fundamental for understanding the whole experience of vulnerability. The Etemic occurs at the fusion between the etic and emic where both are explored together and from this new insights and ways of working are derived. This fusion between the reductionist and humanistic perspective I believe is what is truly needed if services provided are to be effective in addressing the needs of the Gypsy/Travelling community, in reducing the social inequalities and in enabling cultural cohesion which accepts, empowers and values the Gypsy/Travelling community. For practitioners working with the Etemic perspective would enable them to practice in a culturally competent way.

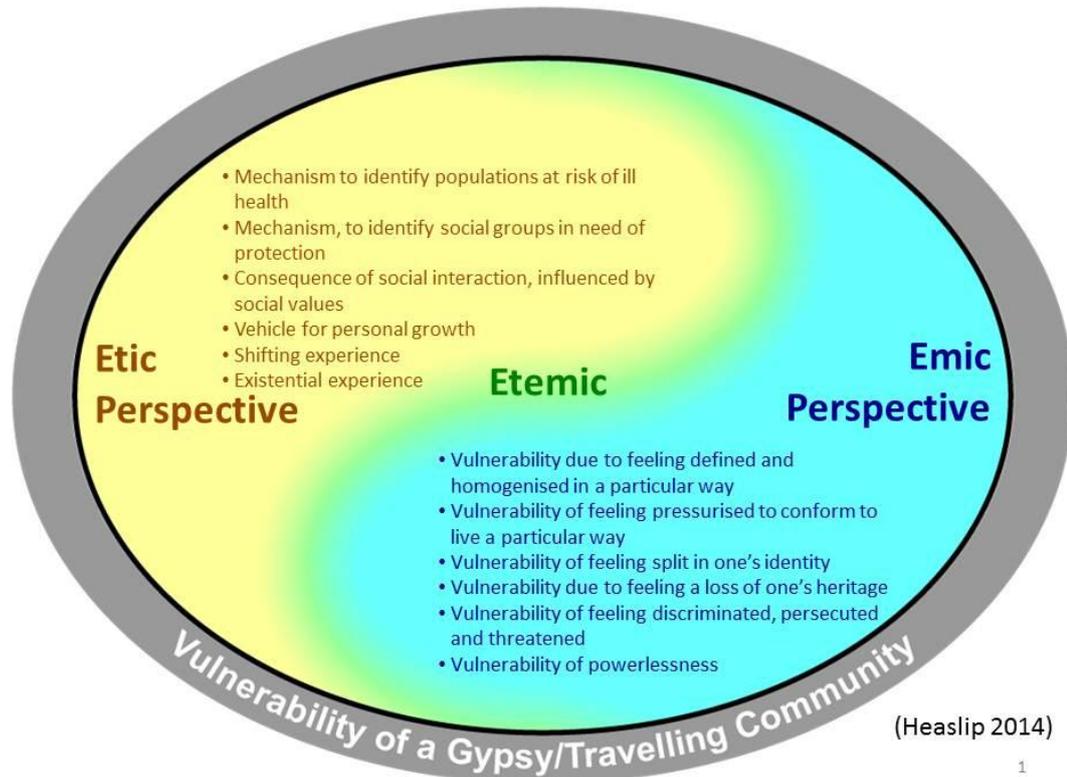


Figure 6 Etemic Perspective of Vulnerability

8.7 Humanisation framework and the Etemic perspective

Lastly this chapter wishes to explore the Etemic perspective of vulnerability within the context of the Humanisation Framework (Todres et al. 2009). The utilisation of the concept of humanisation is growing within the context of care; largely as a response to some highly publicised concerns regarding the provision of care within society (Francis 2013). Within the conceptual framework, eight dimensions (table 12) are presented which can be used to examine the degree to which individuals are dehumanised or humanised.

Table 12 Humanising Framework

Conceptual framework of the dimensions of humanisation by Todres et al. (2009)	
Insiderness	Objectification
Agency	Passivity
Uniqueness	Homogenization
Togetherness	Isolation
Sense-Making	Loss of Meaning
Personal Journey	Loss of Personal Journey
Sense of Place	Dislocation
Embodiment	Reductionist body

This value framework has been used as a mechanism to explore different aspects of care, such as public health (Hemingway 2012) and residential care (Borbasi et al. 2013). This thesis takes this one step further by using the Etemic perspective of vulnerability of a Gypsy/Travelling community alongside the humanisation framework to explore a community experience rather than a service:

- Insiderness - objectification. A central aspect of being human is in our ability to carry a view of life from the inside whilst the contrasting dehumanising view is to see people as labels and to separate ourselves from them by focussing upon the differences between outsider and insider. This study illuminates this, presenting both the contrasting outsider (dehumanising view) that is the etic and the insider, emic perspective. This really shows the breadth of the continuum between the two values as opposed to seeing them as either or constructs. In addition, building empathy in the reader through a phenomenological approach moves away from the dehumanising outsider view towards insiderness.
- Agency – passivity. This dimension could largely focus on agency and passivity at a personal dimension (between carer and cared for). Yet this study expands upon this to explore how wider societal forces impact upon these values. It is clearly evident that for Gypsies and Travellers symbolic power and symbolic violence compound passivity and make it harder for Gypsies/Travellers to have a sense of agency as they can only have a voice by buying into the settled community culture as evident in the constituent of vulnerability of powerlessness.

- Uniqueness – Homogenisation. Gypsies and Travellers may be one of the most homogenised groups within society even though there are distinct cultural differences between Romany Gypsies, Irish Travellers, Showman, English Gypsies and English Travellers. This study clearly highlights how stigma, marginalisation and othering influence this dimension. This dimension also needs to be examined in light of wider discourses that may influence the way in which a particular client group is perceived.
- Togetherness – Isolation. Within the context of Gypsies and Travellers this sense of togetherness is vital. It provides a stabilising force, unites them as a community and equips them to face some of the ongoing challenges they face. This sense of togetherness is being affected by the wider cultural change influencing their community; an example of this is local site policy. Due to restrictions regarding the ability to have an open fire has reduced opportunities for the community to come together thus increasing their sense of isolation. This study also identified that for Gypsies and Travellers there is not a sense of be-longing within the wider community, instead feeling alone. Although a sense of community is really important and strong with Gypsy/Traveller culture, this too is being influenced and for some younger members of the community they are feeling isolated from both Gypsy/Traveller culture and Gorgi culture.
- Sense Making – Loss of Meaning. The next dimension relates to making sense of one's life and the world in which they live. However for Gypsies and Travellers, this sense making is really difficult as they are experiencing a sense of a shifting fractured identity, being forced to live a life at odds with one's own cultural values forcing them to live an inauthentic life which is harder to make meaning from.
- Personal Journey – Loss of Personal Journey. Todres et al. (2009) identify a central tenant of being human is to have a sense of one's past, present and future, and this has one of the largest implications for Gypsies and Travellers. All of the participants in this study identified a sense of having no tomorrow, that they are being eradicated and this feeling has also been identified in other studies (Van Cleemput 2007; Kabachnik 2009), contributing to a loss of personal journey. Levinas identified that freedom cannot only be defined by a political definition but instead needs a historical notion of freedom of the spirit (Hand 2009), yet how do Gypsies and Travellers feel this freedom of spirit when they are contained and

constrained by wider society. In *Totality and Infinity*, Levinas identified that the very goal of human existence has to be situated in the light of infinity (Hand 2009), yet for the participants of this study they could see no future. In addition to having no future the participants also expressed a feeling of having no present, of feeling dislocated within the world. They do not feel as though they belong within the world, instead feel as though they were living in a world which hated and ostracised them.

- **Sense of Place – Dislocation.** This sense of place links to the spatial environment (Todres et al. 2009). The findings from this study identify that the Gypsy/Travelling community feel dislocated from their spatial world. The findings of Phase 1 identified that Gypsies and Travellers feel a connection with the natural earth; they like to be located close to nature. All of the participants (in both phases) spoke passionately and emphatically about a desire to be on the open road, travelling as their ancestors did. Yet this sense of place (travelling) is denied to them due to the legislative changes, resulting in a feeling of being tied and penned in, feeling claustrophobic. Not only has this sense of place been lost in the physical realm, it is also lost in the psychological and social realms. Participants identified that a fire was more than a physical activity, in that it represented a symbolic coming together as a community, sharing stories and cultural traditions. Yet the use of an open fire on a council site is prohibited, thus further increasing the sense of dislocation Gypsies and Travellers feel within the world.
- **Embodiment – Reductionist body.** The last dimension relates to the embodiment sense one has of oneself. For Gypsies and Travellers their embodied self is someone who is free to travel on the open road, this freedom defines who they are. It is an embodied self, which has been passed on from generation to generation throughout history. Furthermore, it was a taken for granted self that has never been stopped or called into question, yet as many more Gypsies and Travellers are becoming more settled their notion of who they are has come under question. It can be seen in Phase 1 that individuals in the settled community question whether a Gypsy/Traveller is still a Gypsy/Traveller if they are settled. This has led to a movement away from an embodiment self towards more of a reductionist perspective of Gypsies and Travellers. This movement increases their vulnerability as it makes them experience their bodies and who they are in different ways through the changing cultural context and their corresponding shifting identities.

From reviewing and exploring the experiences of the participants alongside the Humanisation Framework (Todres et al. 2009) it is clearly evident the links between the lived experience of vulnerability of the Gypsy/Travelling community and dehumanisation. The ETEMIC perspective of vulnerability therefore enables a more detailed application of the humanisation framework towards understanding experiences of vulnerability of Gypsies and Travellers than would be known from just reviewing the etic perspective of vulnerability.

8.8 Limitations of the study

This thesis contributes to the academic discourse that surrounds vulnerability by enabling a broader, more holistic perspective of this human phenomenon. In addition, it is arguing for a new way of seeing vulnerability that transcends both the etic and emic into a new Etemic perspective. It also enhances the professional understanding of vulnerability within the context of a Gypsy/Travelling community by presenting the human experience which until now has been previously missing. There are limitations and notes of caution which also need to be made transparent.

8.8.1 Notes of Caution

The first note of caution relates to transposing this emic perspective to an etic categorisation as Gypsies/Travellers as a “vulnerable community”. Todres (2004) recognises that human vulnerability is an existential experience of the human condition and as such should not be seen as weakness or failure but as both dilemma and gift and this is aligned with my philosophical perspective of vulnerability as a human condition. This study did not seek to ask Gypsy/Travellers if they perceived themselves to be vulnerable, instead it wished to explore times in which they had felt vulnerable. As such a study such as this could have asked the same questions to any individual (whether normatively identified as vulnerable or not) and may have identified similar or opposing experiences.

The second note of caution relates to the term Gypsy/Traveller. This term has been used throughout this study to denote differing groups of Gypsies and Travellers. It is really important to recognise, however, that they are not a homogenous group as such it is important not to assume they are all the same. This study did not seek to explore the differences between differing groups of Gypsies and Travellers instead it sought to explore the phenomenon of vulnerability. It also has to be remembered

that individual groups of Gypsies or Travellers may also have differing values. Within one family in this study there were opposing opinions even though they were all the same type of Gypsy/Traveller.

The third note of caution relates to the cultural identity of Gypsies and Travellers themselves. This study does not present itself as a study which focusses on the cultural beliefs of Gypsies and Travellers; there have been studies which have already explored this (Okely 1983). Rather it is a study which has identified that a core aspect of their experience of vulnerability is related to wider societal change which is impacting upon their cultural beliefs and values.

8.8.2 Limitations

It can always be argued there are methodological limitations to this research; the study did not seek generalisability or validity in a quantitative sense. Instead the focus of the evaluation as to the credibility of this research is explored using the 4 R's identified by Finlay (2011). Firstly rigour, this research has followed a systematic process set out by Giorgi (2009) to conducting descriptive phenomenological research. It opened itself to external scrutiny by colleagues, supervisors as well as fellow phenomenological and social researchers at conferences. The phenomenon of vulnerability (its essence and constituents) has been presented to colleagues and students and it has resonated with them to a greater degree than imagined. It was evident from their body language and feedback that it made them stop and think and touched them in a humanistic way. This was more than was initially hoped for considering the negative public perceptions of Gypsies and Travellers. Secondly, relevance, I would argue that this study has great relevance to individuals working in health and social care as many of these individuals will work with Gypsies and Travellers in the context of their professional practice. Yet this relevance goes beyond just working on a personal level but also includes those who develop and review services as well as politicians working at national levels in health, social care and housing. This study presents and privileges the voices of a highly marginalised and hidden community and through hearing these voices it can enable the development of services which can truly meet their needs. Thirdly resonance, here Finlay (2011) identifies that phenomenological research needs to tap into the spiritual, emotional and artistic dimensions. This really has to be judged by you, the readers, but for me in producing the embodied essence it tapped into me in a way I have never known before. Not being naturally creative or artistic yet I felt compelled

to write this as an alternative way of presenting their essence of vulnerability of this community. Lastly is reflexivity, which relates to my own self-awareness during the research process and this is explored in the final chapter 'My story about their story'.

8.9 Future Directions

The findings from both Phase 1 and Phase 2 provide a window into the world of what it is like to live as a Gypsy/Traveller and clearly identify a very differing perspective of their vulnerability, associated with being a Gypsy/Traveller. Whilst this study was focussed upon the lived experiences of the vulnerability of Gypsies and Travellers, the constituents of vulnerability could be easily transferrable to other groups in society as it offers a human dimension of this human experience, informing us of what it is like to be, within society. Taking the work of Spiers (2000) to the next dimension, moving away from the etic or emic towards the Etemic, as well as the importance of hearing individual voices in order to develop services that truly meet the individuals in line with expectations from professional and statutory bodies highlighted previously.

Undertaking this study in this way has enabled a much greater depth to understanding the illusive phenomenon that is vulnerability and it would be worth utilising this method of inquiry with other normatively identified vulnerable groups enabling individuals within these communities to share their experiences of feeling vulnerable. Incorporating the emic perspectives alongside the knowledge gained from the normative etic perspective to the fused Etemic would enable individual participations and service leaders to have a far greater understanding of the issues affecting individuals and therefore be better placed to develop services which are culturally sensitive that addresses the needs of individuals within these communities. This would enable these services to ensure that care is humanised and truly places individuals at the heart of their services as required by contemporary statutory and professional policies (Council. 2008; Health and Care Professions Council 2008; Nursing Midwifery Council 2008).

8.10 Recommendations

1. Policy Makers

- a) This research identified that the ability to travel was at the core of Gypsy/Travellers identity and therefore to address the ongoing difficulties with unauthorised camping (on public sites). It is vital that more temporary, transit sites are provided to enable Gypsies and Travellers to be able to travel following their cultural norms and traditions.
- b) This study identified that being located close to nature is important for Gypsies and Travellers and therefore it is important that new site developments consider this need to be located near to nature.
- c) A sense of community was also identified to be fundamental for Gypsy/Traveller culture and in order to facilitate this, the ability to be able to have a fire outside is vital. Having a fire is more than just a physical activity; it is also a social space, a coming together of the community to share stories and cooking food in a traditional manner, keeping their cultural identity alive. Therefore in planning site provision space must be identified for residents to be able to have an open fire.
- d) This study highlights that the participants identified a perception that their culture as Gypsies and Travellers was being eradicated due to enforced cultural change. It is also evident that there are poorer health outcomes for this community and further work needs to be undertaken to explore the impact of this loss of cultural identity on ongoing physical and mental health issues of Gypsies and Travellers.

2. Schools

- a) This study has identified that bullying is still an issue (mainly in secondary care education) which contributes to poor educational uptake at this level. It is therefore important that schools collect data regarding accusations of bullying against Gypsies/Travellers to ensure that accurate figures are obtained. They should also take more positive action in schools, presenting an alternative discourse to the one presented in the media.
- b) Further research is also required into experiences of bullying of Gypsies and Travellers within school settings and the perceptions of young people regarding Gypsies and Travellers
- c) It is important that schools have policies in place to ensure that anti-oppressive, anti-discriminatory practice against Gypsy/Travellers is embedded and enforced within schools.

3. Health, Social Care and the Criminal Justice Services

- a) This study has identified that hearing the voices of Gypsies and Travellers enables a more in-depth understanding of their experiences as such it is vital that services actively solicit experiences of Gypsies and Travellers as a mechanism to examine how accessible and culturally sensitive their service is.
- b) It is apparent from this study that participants have experienced discrimination from statutory services as well as the public. Training and Education regarding cultural awareness of Gypsies and Travellers is fundamental for all who work with this community. This training should include some common cultural beliefs of differing types of Gypsies and Travellers in order for practitioners to work more effectively with them. With regards to health care, it is important that all healthcare practitioners have an awareness of the wider cultural values which will impact upon health and decision making of individuals within this community in order to be culturally sensitive to their needs. It is also vital that education of all statutory services employees also includes the examination of personal attitudes and beliefs towards this community.
- c) It is clearly evident that hearing the stories and experiences of this community is really powerful in challenging perceptions regarding them. It is really important that mechanisms to capture and share these experiences are explored with members of the community.

4. Further Study

- a) Exploring the emic alongside an awareness of the etic leading to the Etemic has clearly provided a more rounded exploration of the phenomenon of vulnerability. Therefore, it is worth replicating this study with other normatively identified vulnerable groups.

5. Me, as the researcher

- a) It is important that the lived experience of vulnerability is published in both academic and professional journals in order to present an alternative discourse to the widely published etic perspective.
- b) Future post-doctoral work with Gypsies and Travellers is explored. This would enable aspects that arose from this study but were unable to be explored in depth including, discrimination towards Gypsies and Travellers from health and social care practitioners, and exploring experiences of hospital care by Gypsies and Travellers.

- c) Insights gained from working and researching with Gypsies and Travellers is shared in order to enable others to consider researching and working with this community.

Chapter 9 Reflexive Chapter “My story about collating their story”

9.1 Introduction

Within a descriptive phenomenological study, as part of the phenomenological attitude, the researcher wishes to explore the phenomenon and its meanings without interpretation, explanation or construction. Therefore, it is really important as a researcher that you do not make meanings that are not there, or allow previous knowledge to influence the analysis. Through the process of bracketing, one becomes conscious about current knowledge in order to set it aside to learn something new about the phenomenon. Yet herein lies a paradox, as within qualitative research the role of the researcher as a co-constructor is commonly accepted. Having consciously strived to bracket what it is I knew in the research, I find myself at the end wishing to populate myself back in. Therefore, this chapter shall explore my thoughts, feelings and insights that I became consciously aware of (in order to bracket them) during the research process, and re-examine them to investigate the insights gained as I move forward post-doctorally.

In order to understand my story further there are a number of areas worthy of further reflection and debate including:

- 1) What led me to the study
- 2) Insider...outsider or being in the middle?
- 3) The ‘aha’ moments
 - a. Seeing with new eyes...the embodied response
 - b. The importance of words
- 4) Phenomenology; Philosophy versus Method
- 5) Vulnerability as a human experience
- 6) Dissemination
 - a. Conference Presentations
 - b. Publications

9.2 Why have a reflexive chapter?

Corbin Dwyer and Buckle (2009) believe that the personhood of the researcher, their membership status in relation to participants is an essential and ever present aspect of the investigation. In accepting this to be true, it is therefore fundamental that my reflections during the research process are illuminated, so you as the reader, can judge the validity of this work. Throughout the research I have engaged in reflection (through written diaries and well as audio recorded monologues), the purpose of which was to become consciously aware of my biases and assumptions in order to be able to bracket them. To be free to engage in the research without the influence of preconceived notions (Laverty 2003) regarding the phenomenon of vulnerability.

9.3 What led me to the study?

It can be said that researchers do not really choose their research instead it chooses them (Romanyshyn 2009). For me and this research, this is profoundly the case. If I had asked myself ten years ago whether I would be undertaking a PhD focused on Gypsies and Travellers then the answer would have been a resounding no. Yet I found myself drawn to this particular study for a mixture of personal and professional reasons. Professionally, I had left clinical practice and became embroiled in nurse education, working with and preparing the next generation of nurses. This new journey in my professional life developed further within me an interest in the examination of the world in which we live, and the questioning of the way in which things are. For the first time I felt free to read and critically examine and question the world of nursing. I was exposed to working with people interested in philosophy, who subsequently opened the doors to a world I had never really ventured into before. As not a traditional or natural academic, but someone whose path in learning really developed in adulthood and through experience in professional practice little did I know where this journey would take me.

One of the first responsibilities appointed to me as a newly appointed lecturer was to develop a unit of study for undergraduate student nurses about Vulnerable Groups in Society. Through my reading and discussion with my peers I began to question my previously uncontested professional slant of designating particular groups as vulnerable within health and social care. I also became interested in the

implications of this for professional practice. This unit set the course for my professional interest and practice as a nurse academic and a social science researcher. It became apparent that within health and social care the term "vulnerability" and "vulnerable group" is widely used to denote individuals and groups who may experience poorer health outcomes or be socially marginalized and isolated. What also became apparent during this time was that largely this was a title afforded to these individuals by professionals rather than being self-ascribed. There appeared to be little examination of what vulnerability actually was and what it constituted. Hence the interest in the lived experience of vulnerability and what it means to those actually experiencing it. Throughout the process of undertaking this study I have moved from an uncontested professional bias of perceiving those at risk of ill health as vulnerable towards an appreciation of the multi-faceted nature of vulnerability. For me, vulnerability reflects a kaleidoscope of differing human experiences, some of which are positive, some negative but neither defining nor categorising.

The interest in Gypsies and Travellers in particular came about due to experiences in my personal life. My husband's Nan was from the Showman community. Generations of her family were Showmen, becoming involved in the fairs as employment as Romany Gypsies and she would talk proudly of her life. She spent the first 30 years of her life on the fairs and left at the end of the Second World War; her first love, a showman, was killed and in her grieving she met another soldier who was not a Gypsy. They married and she left the fairs and followed him to Dorset to start a family. My husband was very close to his Nan who was instrumental in bringing him up; as such as a newly married couple we lived with her for a few years. During the time we lived with her she was becoming old and frail and as a result had numerous admissions to hospital. Whilst she was settled (now with hindsight) I would say that she had many traditional Gypsy values which were often incongruent with the values in healthcare. This led to difficulties both for her and the staff assigned to care for her. These experiences ignited in me an interest in experiences of care of Gypsies and Travellers. Thinking now about the impact this may have had on the study, I suppose it did afford me with both a natural curiosity about this different way of living that was not linked to any judgements, and a desire to know more. Often throughout the process of undertaking this PhD I have asked myself did this relationship with Nan affect this research; did it make me sympathetic and therefore less objective. I think that my relationship with her

opened my eyes to a world of which I have previously had no insight into and maybe naturally it provided me with a counter discourse to the one I had previously been presented in the media, so in that way yes I was more open to understanding a different way of living. Whether it made me less objective in the research process I honestly do not think so, I have always been open with my supervisors regarding this relationship and shared every step of the research analysis with them to ensure coherence with the research data and the findings in terms of dependability and conformability of the research.

At the start of the PhD journey I had planned to compare and contrast the nurses' and Gypsies/Traveller views of care. During the process of developing a proposal for the study and reading of the current published literature available, it quickly became apparent that there was little published which enabled the voices of Gypsies and Travellers to be heard. This led to a shifting of focus away from a comparison between the views of nurses' and Gypsies' view of care and become more focussed on exploring Gypsies and Travellers lived experience of vulnerability. As such the study moved me away from my professional discourse as a nurse towards a new uncharted area of a social science researcher. Therefore rather than me shaping the research it is almost as if the research has shaped me both personally and professionally.

9.4 Insider...outsider or being in the middle

Undertaking this research also led me to question the impact of researching a group in which I did not belong, leading me to question and reflect upon my position within the research process. Merriam et al. (2001) queries that to say one is an insider raises the question of 'what is it that they are an insider of?' Conversely being a member of a group does not necessarily mean that the individual has complete sameness within the group (Corbin Dwyer and Buckle 2009). This is especially so when considering the diverse range of different groups which are bracketed together under the umbrella term of Gypsies and Traveller. Likewise, not being a member of a group does not necessarily mean complete difference (Corbin Dwyer and Buckle 2009). For example interviewing Christina with whom we shared aspects of our lives (both in our 30's, mothers to young children and shared occupation as adult nurses). Ultimately these dichotomised positions fail to capture

the multifaceted experiences of some researchers (Song and Parker 1995). Tinker and Armstrong (2008) identify that within the course of a study the researcher can experience moments of being both an insider and outsider as these positions are relative to the cultural values and norms of both the researcher and the participants (Merriam et al. 2001). In addition, Hellawell (2006) asserts that there is not one continuum but in fact multiple parallel ones, for example whilst there may be shared gender identity (elements of insiderness), there may be an age difference between the researcher and participant (elements of outsidersness). Reflecting upon the degree to which this made a difference in this study is difficult to quantify; for the aforementioned Christina I do think it was important as I think it enabled her to feel more secure and comfortable with me (of all the participants she was probably the most nervous at interview). In comparison, when interviewing the men, whom it could be argued we had the greatest degree of difference, many of them appeared very candid and open with me in the interview process.

Thinking back regarding the degree to which my outsider status as a white, Gorgi researcher influenced the process of the research is worthy of a greater depth of reflection than provided in the methodology section. At times, it is certain that being an outsider made the research process more complex especially with regards to recruitment. Phase One recruitment was particularly difficult; Gypsies and Travellers are often invisible within society (especially those living on land they own) and this made identifying and accessing them more challenging. The issue of trust was also problematic, at times there was a sense of the community not really trusting me due to previous bad encounters and experiences, which has been found in other research with this community (Levinson 2010); as well as suspicion with outsiders (Bhopal 2010). An example of this was meeting with Issy (see extract from my reflective diary below)

I turned up at Issy's wagon and said hello and introduced myself. She welcomed me and immediately offered me tea. She prompted me to sit at a table across from her, and made the tea, and then sat opposite me. Looking at her, I could see she was unsure about meeting me, her arms were crossed and she tended to look down rather than look me in the eye. She was nervously holding her cigarette packet and asked me if she could smoke to which I replied "it's your home you can do as you wish" and smiled. This seemed to relax her and we spent the rest of the three hours talking, largely me responding to the questions she posed, and at times she would interject with a little of her life. It felt as though Issy was "sizing me up", deciding whether she could feel open sharing her experiences

with me. I remember being consciously aware that it was not the right time to ask her if she would be involved in the research until the end of our first meeting. Issy agreed to participate and I arranged to meet her again (Extract from diary 11th July 2011).

I have returned to Issy's still not sure if she will be happy talking to me. Again we sit and she makes tea. As she sits and lights a cigarette she asked me "are you going to record our chat this time?" I recognise at that moment she felt able to trust me enough to share her experiences with me (Extract from diary 4th August 2011).

At the heart of this outsider experience I felt was the notion of power. Gypsies and Travellers often experienced power "over" them by individuals within the settled community. Whilst power relations can never be fully equalised in the research process (Bhopal 2009), it can be ameliorated by researchers who are knowledgeable, sensitive, and conscientious (Peternalj-Taylor 2005). I recognised that for Issy building a rapport was fundamental to her and I ensured that my research agenda was secondary in our initial meeting, and instead spent time getting to know her and honestly answering any questions she posed of me. Many of these skills I was perhaps subconsciously drawing upon at this time, was my background as a district nurse who was used to looking after patients in their own homes and therefore was skilled in assisting people to feel comfortable with me (a stranger) in their own private domain. I believe that for this research spending time enabling people to feel comfortable to share their story was fundamental in ensuring credibility of the data.

I consciously strove to ensure that each of the participants I spoke to retained a sense of power in the interview process. For Christina (another participant in Phase 1) she requested the interview took place at her work and she asked to have a colleague present during the interview as she required this support in order to feel comfortable talking to me (even though we had met before and were both registered nurses). These early encounters really highlighted the importance of flexibility during data collection, something that ended up being fundamental in Phase 2 when often my planned one-to-one interviews really became group interviews as other family members would join the discussion. This led to interesting challenges methodologically (explored previously in Chapter 6), yet in this flexibility I was

moving away from outsider and into insider, to the participant's way of living which I think led to gathering much more authentic and honest accounts.

Another aspect of the insider/outsider perspective in this research was that my husband's Nan was from the showman community and the desire to explore this community came from seeing her experiences of healthcare towards the end of her life. I never hid this from the participants and would share this story in response to their questioning as to why I was interested in Gypsies and Travellers. My rationale for sharing this aspect was honesty, there have been times in the past in which Gypsies and Travellers have felt manipulated in the research process (Greenfields and Home 2006) which further perpetuates a distrust of people outside the community. Lavery (2003) asserts that trust is fundamental to qualitative research in ensuring quality of the data. Sharing this aspect of my personal life could have resulted in me being accepted as an "adopted outsider", a term coined by Clingerman (2007), and assigned the status of being accepted and trusted as there was a family connection to the Gypsy/Travelling community. This relationship I think positively impacted on the participants being willing to talk to me and share their stories, maybe they felt I would be more receptive to hearing them and honestly I probably was.

Being an outsider in this research also brought benefits as it enabled me to be open to seeing the participants' experiences through their eyes, rather than making a comparison to my own and this has been found in other research (Tinker and Armstrong 2008; Innes 2009). This is really important in descriptive phenomenological research where the essential purpose is to see a phenomenon with fresh insights and to learn something more about it. The researcher must be aware of one's past knowledge and insights and bracket it so it does not influence the analysis of the participants' experiences; arguably exposing oneself to a new culture facilitates this process. Whilst I had listened to Nan's stories of her life and her childhood, we had never explored whether she felt vulnerable so I had no insight into this particular phenomenon with this particular group. During the process of data analysis I was not even aware of Nan or indeed of any participant beyond the individual whose transcript I was working on at that time. Each participant's transcript required me to enter their world and I did this systematically by only working on one transcript at a time and completing that analysis before moving on

to the next. On reflection, I do not necessarily believe that an ultimate judgement of insidersness or outsidersness is best; rather it depends upon each individual participant in each particular study.

Lastly, I believe that the title of nurse also afforded me a sense of status which assisted in the development of a trusting relationship. The participants would often ask me about my experiences of caring for Gypsies and Travellers and often identified a willingness to share their experiences in order to enhance the care provided to other Gypsies/Travellers. It was as if the very label of nurse privileged me with a basic level of trust, perhaps due to the positive public perceptions of nurses by society. Whilst I feel my professional background enhanced the research in many ways I was also aware that it could potentially have influenced the research in that it could have clouded my perceptions of their experiences or indeed focussed their experiences to exploring health vulnerability. Whilst fear of the future and declining physical health was one of the themes identified from the findings in Phase one, it was just one aspect of vulnerability that the participants identified, therefore any impact it may have had, I feel, was minimal.

9.5 The 'aha' moments

9.5.1 Seeing with new eyes...the embodied response

One of the key aspects within descriptive phenomenology is to suspend your perspective and way of seeing the phenomenon in order to learn something new, which Finlay (2011) refers to as the 'phenomenological attitude'. In this respect being an outsider in the research process can assist with this. Below is an extract from my reflective journal capturing the first time I was able to see the situation with new eyes:

"...listening to Tommy, for the first time I think I get it. He was telling me about a recent admission to intensive care unit (ICU) and how he felt when he started to regain consciousness. He told me how he did not want to be there and would spend most of the day trying to escape. Previously I may have looked upon this story through my nurse's eyes and maybe have got frustrated because as nurses, we would be trying to help him and confused as to why he was fighting us. Yet today I witnessed Tommy's story through new eyes; through his eyes. Tommy chooses to live "off the grid", as such his interactions with people are limited and directed by him, he has a

generator for electricity and no running water, his wagon is located in a field two miles away from the nearest village. As he was telling me that he just did not want to be there and I sat and looked at where he lived and physically-felt silence, for the first time in my life the contrast between his world and the world of the ICU became apparent and for the first time I understood why he behaved as he did...” (Extract from diary 22nd July 2011)

My embodied experience of his “lived experience” is a really valuable insight, as it demonstrated how I suspended my own way of knowing to be open to a new way of seeing the world (in this case the hospital environment). This insight I share with students to highlight to them how it may feel to be cared for in such an environment, which is a direct contrast to how Tommy chooses to live his life. As nurses we may be frustrated with Tommy who may appear to be fighting us when we are simply trying to help him, yet this insight of his fear and vulnerability may assist the nurses in understanding his actions rather than simply judging them. It also offers practical discussion and leads to debate as to how his vulnerability can be ameliorated, for example locating him near a window so he can see outside, as nature is of comfort to him. Methodologically for me this is the greatest gift that phenomenology offers and I do not think I would have gained this insight if I had chosen an alternative method.

9.5.2 The importance of words

Gunaratnam (2003) argues that the research process itself can perpetuate conceptions of race as it can essentialise experiences of individuals and groups. This was something I was consciously aware of during the research and moving forward after the research has been completed. I find myself stressing when I am sharing this research with students that these were the experiences of the participants I had spoken to, and also reminding them that it is not the goal of qualitative research to be able to generalise from the findings. I also hasten to remind them that even though this study is titled “experiences of vulnerability from a Gypsy/Travelling perspective: a phenomenological study” it is important to remember that there are distinct differences between differing types of Gypsies and Travellers and they are not a homogenised group, each with their own particular values and beliefs and this was particularly pertinent with the title afforded to them. I knew from undertaking the literature review (Chapter 2) that Romany Gypsies prefer the term Gypsy whilst Irish Travellers find this term offensive and such prefer

the term Traveller. As such during the interviews I consciously made sure that I used the appropriate terminology when interviewing the participants. However I unwittingly made mistakes, for example when interviewing Christina (Romany Gypsy in Phase One) whilst introducing the study I utilised the term Gypsy/Traveller, yet during the interview she shared with me that for her the word Gypsy should only be used within the community as it is stigmatising if used by someone outside, instead the term Roma is preferable. Yet others (Rawnie, Alanna, and Orla Romany Gypsies in Phase Two) found the term Gypsy acceptable. Conversely Shauna, Daisy and Cora, whilst Romany, actually referred to themselves as English Travellers, and I wonder in part if this occurred due to a desire to highlight their status as British citizens as opposed to eastern European Roma. Difficulties regarding terminology also arose when interviewing Jimmy, an Irish Traveller, as I was consciously aware that Irish Travellers prefer the term Traveller as such Traveller was the term used, yet when he referred to Romany Gypsies he too would refer to them as English Travellers as the term Gypsy is so abhorrent to him he does not use it at all. The differing use of terminology within the community has also been identified in research with Gypsies and Travellers by Levinson (2010) who asserts that there remain unresolved issues regarding the representation of different voices under the umbrella term of Gypsies and Travellers. This is a key issue to note when working professionally with this group and utilising the wrong language could inadvertently cause offence and is therefore of paramount consideration to health and social care professionals.

9.6 Phenomenology; Philosophy versus Method

At numerous points during the study I presented my work at conferences, in order to open debate and discussion regarding my chosen topic area. The second time I presented my study I focussed upon the methodological approach taken at the Human Science Research Conference (the main phenomenology conference). This conference really opened my eyes as to the ongoing tensions within the phenomenological community regarding the ongoing divide as to whether phenomenology is a philosophical endeavour or a research method in its own right. At the beginning of this PhD journey I decided to utilise descriptive phenomenology due to a desire to hear the participants' own voices without an additional interpretive viewpoint. As a novice researcher the guidance offered from Giorgi in his approach was attractive and logical to follow. Yet it was really at this conference that I began

to realise and appreciate how polarised the views regarding phenomenology are. It made me think that the community is really like a dysfunctional family who belong, but do not always get along. This has made my journey a little precarious at times, especially when sharing my work with other phenomenologists that do not value the contribution it can make as a research endeavour in caring and health sciences. During the summer of 2013 I had the opportunity to attend a summer school hosted by Max Van Manen, Bas Levering, Kathy Adams and Michael Van Manen. I was aware of Van Manen views regarding phenomenology and his open critique of Giorgi and how he did not perceive it to be phenomenology at all. I bravely informed them of my approach and would openly challenge his perception that Giorgi's approach led to an unquestioning, unthinking analysis of the data, as this was at odds to my own experience of using Giorgi's approach. At times, I found the process of analysis using Giorgi's approach (2009) very complicated especially with regards to what Finlay (2011) refers to as the dance between the whole and the parts of the data and how I would spend days just listening to the transcripts and trying to understand what it was the participant was trying to tell me. This I captured in the extract from the reflective diary below:

"I don't know where the day has gone, I feel frustrated....I don't appear to have progressed. My plan was to analyse an interview each week of my study leave but now I am not sure this is realistic.... I just sit and read and listen and think..." (Extract from diary 18th April 2013).

This experience of frustration was mirrored when I was working with the analysed transcripts trying to identify the essence of the phenomenon of vulnerability:

"Went to see Les today...I felt as though I had lost my way and couldn't see a way forward. I have read and read and read but seem to be lost in the trees and don't know where I am going. Les felt as though I am too close to the parts of the data and have lost sight of the whole, I am going to follow his advice and take a step back, put the transcripts away and just write..." (Extract from diary 26th June 2013).

At times, during my debates with Max and Bas it felt like I was 'entering the lion's den' however it enabled me to become confident in my ability to defend the approach I had taken which was good training for the eventual viva. Yet, I was also open and receptive to hearing about phenomenology as a philosophy as this would enable me to be a more rounded phenomenologist. I was attracted to Van Manen's approach to the writing of the data (for a greater review please see chapter 7),

ultimately this led me to fuse descriptive and interpretative phenomenology, not in the analysis of the data but in its interpretation in the discussion chapters and commenced a fire in me for reading philosophy.

9.7 My vulnerability in exploring their vulnerability

Research by (Dickson-Swift et al. 2007) on 30 qualitative health researchers identifies that undertaking qualitative research can lead to researchers facing challenges such as:

- 1) Entering the lives of others
- 2) Developing rapport
- 3) Self-disclosure
- 4) Reciprocity

Reflecting upon this research it was evident that at times throughout this research I became vulnerable through exploring their vulnerability. In order to develop and build rapport with the participants who shared their stories with me it was really important, I felt, to interview them where they felt safe and secure. This often resulted in me travelling to a postcode but yet not really knowing where I was going and what I would encounter when I got there. To some degree I was used to this, due to my previous professional background as a district nurse, yet I remember often feeling anxious as I left my car wondering as to what reception I would receive. Part of developing and building rapport I feel is honesty and transparency and this, I felt, was vital to the research, therefore I would often find myself answering questions regarding my own personal life, which I felt was a fair trade considering they were also sharing theirs, therefore a sense of reciprocity begins. This led me to being open to enter their lives and their worlds and at times this was difficult (see extracts from reflexive diary below):

“Out data collecting again, went to visit a lady who was in her late thirties who has a diagnosis of terminal cancer. When I arrived it was clearly evident her young daughter was struggling caring for her, she was sat on the edge of a couch and smoking a cigarette (whilst also having oxygen via nasal cannula). It was evident that she was very uncomfortable and struggling to move due to her stomach ascites. Her stomach was incredibly swollen and every time she moved, she had a facial grimace. Her eldest daughter (in the late teens) was crying and immediately began telling me what a difficult night they had all had. It clearly became apparent that it was neither appropriate nor ethical to interview her regarding her vulnerability. Yet it was

clear they as a family were struggling. I sat and listened to both of them and immediately through my district nursing knowledge could think of various things which should be implemented to ease both of their suffering. They shared with me they did not feel able to talk to the nurse and share their thoughts with her. Through talking with them they agree to ring and ask the district nurse to call and I wrote them a list of all the equipment they should ask for. As I sit and write this, I can feel myself getting angrier at my colleagues and my profession which is allowing such suffering to occur, and it makes me miss my clinical practice.” (Extract from diary 5th February 2013)

This extract highlights how reciprocity that can occur when undertaking qualitative research. It was not appropriate to interview her (even though she was willing) and yet I still felt a sense of responsibility to her. This responsibility may have been influenced by how receptive and generous the community had been to me and I felt the need to give something back, alternatively I am a nurse and therefore also find it hard to ignore someone who is suffering.

One of the most difficult interviews I had was with Rawnie, a 23 year old Romany Gypsy who is married to a Gypsy and has a young baby (only months old). It was clear when interviewing Rawnie that she was unhappy with her life, she felt trapped and was very sad. She acknowledged during our talk that I made her feel depressed when she heard herself talking of her life. I had a sense talking to her that she was not happy in her marriage, and I suspected there was some intimate partner violence occurring on occasions, from both her demeanour and what she shared. Yet Rawnie also asserted to me that divorce would bring shame on both her and her husband’s family. It was during this interview that I felt the most helpless and consciously had to struggle with my thoughts following the interview:

“Met Rawnie today – I cannot believe that someone so young could feel so sad and so trapped. To be honest I struggle to understand why she doesn’t leave if she is so unhappy and return to her family” (Extract from diary 7th Dec 2013).

Thinking back about Rawnie I had to acknowledge the differences in our cultural beliefs as this was affecting my ability to understand her story. As a woman from the settled community, I have always been fiercely independent and this led me to ensuring I also always had financial independence from any man. Therefore if our situations were reversed I would leave yet I had to acknowledge I perceived her situation through my cultural discourse and not hers. Having become consciously

aware of this I was then able to suspend my beliefs about her life and enter her perception.

Often I am asked by students if I am pro Gypsy, in addition I have also heard myself referred to as the “Gypsy lady”. This has led me to question am I pro Gypsy and if so could this have affected the validity of this work. Johnsen (2010; p59) who has worked with other marginalised communities argues:

“If I am really involved, it will probably affect me and do something to me; my values are challenged, I am in a sense transformed, or my insights are changed, in ways that influence how I perceive and interpret situations”.

This, I think, is true for me, am I pro Gypsy? I certainly have a much better insight into their world, and their vulnerability. Through this work I was able to meet a large number of individuals and therefore challenge some of the negative discourses that I had been exposed to that surrounds them. These insights into their world I share and where appropriate challenge some of the negative perceptions that surround them. For example, teaching some first year sociology students about phenomenology I use this research in order to bring phenomenology alive. One of the questions I was asked was regarding the waste that often Gypsies leave by the roadside, and I was able to challenge what else they were able to do when there were no services provided to dispose of their waste by questioning the students what would happen if we did not have a refuse collection. If this makes me pro Gypsy, then I accept this. However I also think that individuals would not undertake qualitative research unless they are willing and receptive to hear the world of the other. Therefore do I think it influenced this research, and the honest answer is probably, as I would imagine my body language would have mirrored my feelings of being open to and willing to hear about their experiences and this will have impacted on developing a rapport with participants which would have led to them feeling more comfortable in expressing their thoughts and feelings with me.

9.8 Sharing their story

I have already mentioned as part of reciprocity I felt a sense of responsibility towards the community to share their experiences. I felt they trusted me to share

their story and their worlds in an environment in which they currently have no voice. As previously mentioned in chapter 2, Gypsies and Travellers have previously felt over investigated for the purpose of research which failed to bring about change (Greenfields and Home 2006). I was conscious of this throughout the study and felt a moral obligation to ensure that the research was used in order to enhance practice.

Shapiro (2008) argues that instead of drawing close to those who are suffering, human nature almost does the opposite, arguing there is an equal if not stronger desire to pull away and detach. The implications of this for health and social care practitioners are huge, as there may be a split in their professional responsibility and their natural instinct. Research by (Zerwekh 2000; Stanghellini and Rosfort 2013)) on nurses' responses to working with disenfranchised groups identified a separation, in that disenfranchised clients were perceived to be separated from human society as people who bring out fear in others which resulted in the nurses backing away from them. The research also identified what enabled nurses to care for these individuals was the human connection of honouring their humanity, knowing their humanity and sharing their own humanity. Yet this is very difficult to achieve especially when working with individuals and groups who do not have the same shared cultural norms and values. Stanghellini and Rosfort (2013; p 340) raises for me a fundamental question for health and social care education which is, "how can people empathetically understand the expressive phenomena of other people if we do not see the other as an embodied person embedded in a common human world". They argue that a second order empathy is required; here the individual needs to set aside their natural predisposition that makes them try to make sense of that person's experience as if it took place in their own world and instead reconstruct existential structures of the world of the other so they can attempt to understand the others' experience. This is what I am aiming to achieve in my teaching with students by seeing beyond the label of Gypsy/Traveller and instead focussing upon the human being and our shared humanity through the sharing of the essences.

In addition to teaching with students I have been keen to share the experiences of my participants with academic colleagues both nationally and internationally. The purpose of which was to share the individual's stories with a view to challenging

perceptions and attitudes of educators who are role models to students. At times, these conferences were also to stimulate academic debate regarding chosen methodology and to open myself and my work to scrutiny of others within the field. In addition to this I also edited a text book for health and social; care practitioners about vulnerability (see below) and included not only my literature review but also aspects of the experiences of Gypsies and Travellers. The rationale for this was to reach a far greater audience than the students studying at the institution in which I work. I have also worked with the local council to develop a video in which Gypsies and Travellers talk about their experiences. This is extremely powerful as students and practitioners can see a visual stimuli as well as a written story. Whilst perhaps not traditionally part of a PhD I felt it was important to add to this chapter as for me, the dissemination of the research is of equal importance especially when the purpose of this research was to enable voices that traditionally were not heard or privileged in the academic discourse to become so.

9.8.1 Conference Presentations (Concurrent Papers)

22-25th June 2014. **Heaslip, V.**, Cooper, K., Ryden, J., Why understanding the lived experience of vulnerability is fundamental to exploring the value base of care, NET/NEP 5th International Nurse Education Conference, Noordwijkerhoutin, Netherlands.

21/6/2013. **Heaslip, V.**, “Hidden voices.....guiding the way”, Phi Mu Inaugural Conference, Bournemouth University.

27/7/2011. **Heaslip, V.**, ““The kaleidoscope of vulnerability””; proposing a methodological approach enabling breadth and depth of exploration, 30th International Human Science Research Conference, St Catherine College Oxford.

7/9/2010. **Heaslip, V.**, “Shifting Sands of Vulnerability”, 8th International Qualitative Research Conference, Bournemouth University.

9.8.2 Publications

Heaslip, V., Ryden, J., 2013 (eds). *Understanding Vulnerability; A Nursing and Healthcare Approach* (EDS). Oxford: Wiley Blackwell.

Willetts, C., Thomas, G., and **Heaslip, V.**, 2013, *Psychosocial experiences and implications of vulnerability*. In **Heaslip, V.**, Ryden, J., 2013 (eds). *Understanding Vulnerability; A Nursing and HealthCare Approach*. Oxford: Wiley Blackwell.

Heaslip, V., 2013, Understanding Vulnerability. *In* **Heaslip, V.**, Ryden, J., 2013 (eds). Understanding Vulnerability; A Nursing and HealthCare Approach. Oxford: Wiley Blackwell.

9.8.3 Videos

Wiltshire Council Traveller Liaison Service., **Heaslip, V.**, 2013. Wiltshire Voices Gypsies and Travellers. Online, available from <http://truevisiontv.com/wiltshire-voices---Gypsies--Travellers>

[Accessed 16.01.2014]

This chapter has shared my thoughts and feelings during the research, detailing how and why certain decisions were made as well as exploring how I have tried through the research to be consciously aware of my own thoughts, feeling and judgements in order to push them to the side, to be open to sharing the world of another. In doing so, it does (perhaps inadvertently) demonstrate my growth both personally and professionally throughout the duration of this research. It has also enabled me to begin to think about where this work goes post-doctoral. I am really interested in developing this work further by examining professional staff attitudes towards Gypsies and Travellers as well as exploring the impact that sharing their life experiences of vulnerability has upon these.

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Race Equality Act 2010

Race Equality Scheme 2008

Race Relation Act 2000

Glossary

Gorgio, Gaujo – term used by Romany Gypsies to denote a non-Gypsy

Country...man/woman/folk – term used by Irish Travellers to denote a non-Traveller

Silky – Trap used alongside horses to ride on

Appendices

Appendix 1 Literature Review Summary Chart – Vulnerability Research Papers

Key – Types of research		
Mixed methods	Qualitative	Qualitative

UK Literature

Author Year of publication Title of Article	Aims Objectives	Method Analysis	Participants Sample	Major Findings	Recommendations Limitations	Issues raised for the proposed PhD study
Abley, C., Robinson, L., 2011. Improving interprofessional practice for vulnerable older people: gaining a better understanding of vulnerability. Journal of Interprofessional Care. 25. 359- 365.	Study exploring patient centred care for vulnerable older people in the community.	Social constructionist methodology Focus groups Constant comparative method	Purposeful 42 participants (21 older people and 21 professionals)	There was a difference between older people and professional construction of vulnerability. For older people vulnerability was an emotional response to being in a specific citation with little or no control. For professionals vulnerability defined certain risk factors or characteristic of a vulnerable older person	Limitations included lack of men in the study and lack of GP	This highlights the differences between the etic and emic perspective of vulnerability. As well as the importance of listening and hearing people voices who are experiencing feeling vulnerable.
Appleton, J., 1994. The Concept of Vulnerability in Relation to Child Protection: Health Visitors'	Aim of the paper is to focus on the health visitors perceptions on the concept of vulnerability.	Broadly Qualitative. Questionnaire, using different type of questions, some	Postal Survey of 102 HV (58% response rate).	Lack of consensus and clear definition of the term vulnerability. It was also apparent that there is ambiguity surrounding the term, only 3% of the sample felt that the term should not be used as it is subjective and value laden.	Use of the term vulnerability needs to be explored further due to its current ambiguity yet paradoxically it plays a central role in health visiting practice.	This study supports the need for a greater understanding of the phenomenon of vulnerability.

Author Year of publication Title of Article	Aims Objectives	Method Analysis	Participants Sample	Major Findings	Recommendations Limitations	Issues raised for the proposed PhD study
Perceptions. Journal of Advanced Nursing 20 1132-1140.		open some likert. 12 in depth interviews		Highlighted the complexity of the concept by words such as 'multiple factors' 'complex nature' 'combination of factors'. All respondents felt that vulnerability was a non-permanent state. Vulnerability caused by combination of medical, psychological, social and cultural factors		
Koffman, J., Morgan, M., Edmonds, P., Speck, P., Higginson, J., 2009. Vulnerability in Palliative Care Research: Findings from a Qualitative Study of Black Caribbean and White British Patients with Advanced Cancer. Journal of Medical Ethics. 35 p440- 444.		Interviews with thematic analysis	3 South London Boroughs. 29 black Caribbean and 19 white British	5 types of vulnerability identified Communicative vulnerability – impaired ability to communicate because of distressing symptoms. Institutional vulnerability - those who existed under the authority of others at time of study – e.g. hospitalised this had issues relating to confidentiality of interviews, dress of clients which could impact upon the research e.g. hospital gowns, position of patient. Deferential vulnerability – those who were subject to informal authority or independent interests of others. Medical vulnerability – concern for participants who have serious and distressing medical conditions. Social Vulnerability – Able to consent but may belong to an undervalued social group.	Identified limited research conducted exploring vulnerability of participants during research, and identified that it should not prevent research occurring and each research and participants needs an individual's assessment of their potential vulnerability.	It could be argued under research terms that the Gypsy/Travelling community is a vulnerable group due to marginalised and minority status, yet this should not prevent research from occurring – it is about ensuring as much as possible the rights of participants are explained as well as ensuring as much power balance as possible.
Maxwell, C., 2006. Understanding young Women's Sexual	How useful the concept of vulnerability is in providing a framework for	Narrative In depth interviews and focus group discussions	30 young women (n=17 from a vulnerable sample and 13	Findings supported the importance of social context (and its complexity) as central to understanding differences in risks to negative social outcomes such as STI, sexual coercion and unplanned pregnancy.		Whilst vulnerability was defined by certain characteristics, it was not identified how these were raised as

Author Year of publication Title of Article	Aims Objectives	Method Analysis	Participants Sample	Major Findings	Recommendations Limitations	Issues raised for the proposed PhD study
Relationship Experiences: The Nature and Role of Vulnerability. Journal of Youth Studies. 9(2) 141-158.	understanding contemporary differences in young women's sexual relationships.		from a less vulnerable sample). Vulnerability was defined by educational level, history of substance misuse, experiences of youth offending, homelessness, teenage parenthood, and current levels of adult support and supervision. And			important aspects of vulnerability. How do practitioners know what vulnerability is to the individuals experiencing it?
Leroux, P., Sperlinger, D., and Worrell, M., 2007. Experiencing Vulnerability in Psychotherapy. Existential Analysis 18(2) 315-328.	Can you tell me in as much detail as possible what it was like for you to experience 'being vulnerable' in psychotherapy?	Descriptive Phenomenology	5 women, 1 man. Mean age 37 (age range 30-42)	Themes General vulnerability Safety and protection Being exposed Time and boundaries Being left Body Dilemma Tension Power Dynamics Meeting and miss meeting	Further research on Slavin's work on vulnerability specially the sense that one has that each has some investment not only n one's own agenda but will see the others as a subject in their own right and secondly that feeling that each shares some measure of vulnerability in the relationship.	This research was the closest research conducted to the proposed study. It utilises the same methodological approach, however the group of clients are different.

Author Year of publication Title of Article	Aims Objectives	Method Analysis	Participants Sample	Major Findings	Recommendations Limitations	Issues raised for the proposed PhD study
Stewart, E., 2005. Exploring the Vulnerability of Asylum Seekers in the UK. Population, Space and Place. 11 499- 512.	To understand the experiences of asylum seekers living in the UK, particularly their vulnerability over time.	Semi structured Interviews, snowballing technique.	25	<p>Suspended Identity “We just have the right to breathe” – waiting for immigration decisions was like living in limbo, not feeling a sense of belonging.</p> <p>Spatial Manifestations of Vulnerability “I don’t go to Public Places” – physically separated from host society (due to housing areas) which prevents social interaction. Lack of financial resources partially excluded from commercial spaces in cities. Feeling vulnerable in public spaces due to fear and lack of social connection. Negative perceptions of asylum seekers lead to isolation.</p> <p>Hiding Identity “ I feel embarrassed to be an asylum seeker” – Individuals felt uncomfortable with the label reporting feelings of shame</p>	<p>The results demonstrated that a suspended identify was more likely to cause extreme personal effects, indicating that a focus of attention should not only be upon the ‘Vulnerable’ individuals but also state mechanisms which cause of exacerbate experiences of vulnerability.</p> <p>Further theoretical advancement exploring how vulnerability of experience in time and space.</p> <p>Need to further understand cumulative vulnerabilities.</p>	It can be argued there are similarities between Asylum seekers and the Gypsy/Travelling community especially with regards to negative public portrayals and stereotypes, being physically separated from society due to the locality of permanent sites.

Literature Review Summary Chart – Research Papers

Non UK Literature

Author Year of publication	Aims Objectives	Method Analysis	Participants Sample	Major Findings	Recommendations Limitations	Issues raised for the proposed PhD study
Ahern, J., Galea, S., Hubbard, A., and Karpati, A., 2008. Population Vulnerabilities and Capacities Related to Health: A Test of a Model. Social Science and Medicine. 66 691-703.	<p>Variability in population health between socioeconomically vulnerable neighbourhoods would be explained by accounting for other vulnerabilities and capacities of those neighbourhoods.</p> <p>Variability in population health between vulnerable neighbourhoods would be explained by accounting for the distribution of individuals' socioeconomic status.</p>	<p>Case Study</p> <p>Dependent variable - Age adjusted mortality rates for 12 publically available causes of death from 2000.</p> <p>Independent variables – Socio economic vulnerability, vulnerabilities/capacities Social control, Quality of local schools, Unemployment, Low education, Distribution of individual income.</p>	59 New York City Community Districts.	Results clearly supported the first hypothesis that variability in population health can be explained by accounting for other vulnerabilities and capacities of neighbourhoods.	Understanding the constellation of underlying factors that come together in a population may provide more information on how population health condition develop, how they will respond to perturbations such as stressful or protective events, and eventually inform us about ways which we may improve population health.	
Boles, R., Roberts, M.,	Children's	Family	46 children aged 4-	Children were significantly	Small sample size	Interesting that

Author Year of publication	Aims Objectives	Method Analysis	Participants Sample	Major Findings	Recommendations Limitations	Issues raised for the proposed PhD study
Brown, K., Mayes, S., 2005. Children's Risk Taking Behaviours: The Role of Child-Based Perceptions of Vulnerability and Temperament. Journal of Paediatric Psychology 30(7) 562-570	perceptions of vulnerability to risky home situations are examined to determine possible links to their observed behaviour in a simulated home hazard environment.	Information Form Temperament Assessment Battery for Children – Revised (37 item normative based Likert type questionnaire) Injury Vulnerability Assessment for Children (20 photographs of a child aged 5 interacting in a home environment) children how to decide the likelihood they would be injured along a Visual Analog Scale (VAS), lastly clinical observations.	7 and their caregivers	more likely to indicate lower perceptions of vulnerability to injury as their actual risky behaviour increased (Pearson's correlation tests). Boys more likely to engage in risky behaviour. As age increased so to, did perceptions of vulnerability rating increase.		quantitative measurements for vulnerability are identified – yet it is also recognised that the term is ambiguous.
Clark, C., 2007. Understanding Vulnerability: From Categories to Experiences of Young Congolese	Not explicit	Participant observation, Semi structured interviews, focus group	2 sites Kampala and Kyaka II. 50 individuals. Different ages, sex, ethnicity and class	Fixed, categorical ideals of vulnerables do not reflect the more complex reality of dynamic vulnerability in shifting relationships and contexts.	Instead of projecting pre conceived categories onto populations there is a need to better understand what	This study supports the need for a better understanding of the term vulnerable in different contexts

Author Year of publication	Aims Objectives	Method Analysis	Participants Sample	Major Findings	Recommendations Limitations	Issues raised for the proposed PhD study
People in Uganda. Children & Society. 21 284-296		discussions, oral history and individual writing exercises.		We have transformed the adjective vulnerable into the noun vulnerables, and respond to this rather than examining and exploring the root causes of vulnerability. Vulnerable label can result in victimacy and undermine local coping strategies.	vulnerability actually means to people in varying contexts and relationships. Need to explore power structures in the context of vulnerability. Posing the question, vulnerability to what? Enables the analysis of the power structures and therefore better understanding of root causes of and appropriate responses to vulnerability than the categorical vulnerables approach.	and relationships.
Dogan, D., Ertem, I., Karaaslan, T., Forsyth, B., 2009. Perception of Vulnerability Among Mothers of Health Infants in a Middle-Income Country. Child: Care, Health and Development. 35(6) 868-872	To assess the use of the Child Vulnerability Scale (CVS) in a middle income country (Turkey), the utility of the CVS when used with younger children and rate and correlates of maternal perceptions of vulnerability	Cross sectional observational study Child Vulnerability Scale (CVS) SPSS 11.0, Cronbach alpha to determine internal consistency of CVS, Univariate analysis to	519 children (264 boys and 255 girls) Children aged 1-30 months who from birth onwards received preventative healthcare at 2 university affiliated community well child care clinics. Inclusion criteria Healthy singletons with birth weight of	6% of the sample was perceived as vulnerable by their mothers. Socio demographic factors such as child gender, birth order, maternal or paternal age and educational level and history of threatened abortion during pregnancy was not found to be associated with higher vulnerability scores.	Generalisability limited due to sample. Selection bias may have led to over inclusion of mothers who are more attentive to the health of their children. Further studies needed to determine the rate, correlates and effects of perceived vulnerability on children in low and middle income countries.	Quantitative measurements of childhood vulnerability.

Author Year of publication	Aims Objectives	Method Analysis	Participants Sample	Major Findings	Recommendations Limitations	Issues raised for the proposed PhD study
	among healthy young children.	determine rates of vulnerability. Chi-Square for categorical variables.	equal to/greater than 2500g and at gestational age of 37 weeks+, growth between 5-95 percentiles and paediatric evaluation and chart review concluded they were healthy.		Research needed to determine whether perceived vulnerability may be an adaptive and harmless cultural phenomenon or whether it has negative implications for children in low and middle income countries similarly to high income countries	
Forsyth, B., McCue Horwitz, S., Leventhal, J., Burger, J., Leaf, P., 1996. The Child Vulnerability Scale: An Instrument to Measure Parental Perceptions of Child Vulnerability. Journal of Paediatric Psychology. 21(1) 89-101.	Further develop and validate the Child Vulnerability Scale.	Child Behaviour Checklist, paediatrician form identifying psychosocial problems. Paediatricians listed PMH identifying whether they were acute/chronic and graded these as mild, moderate or severe. Chi square analysis	1,095 mothers and children (4-8yrs) participated; these were identified from paediatricians' offices.	Perceived vulnerability is a long lasting or continuous process. Certain illnesses such as asthma may make a child vulnerable; however it is also true that not all children with such illnesses are vulnerable. Important validation of the tool that when both variants are present over half the subjects are categorized by the revised tool as vulnerable whereas when a child has no medical illness and a parent has never feared that a child might die, it is rare (only 1.5%) for a child to be categorized as vulnerable.	Further research is required to validate the tool more widely within the general population	
Gleason, T., and Evans, M., 2004. Perceived Vulnerability: a	To examine individual differences in	Parent Survey – part fixed questions part	n=47 (18 boys, 29 girls) from 2 preschools in a	63.8% of the pairs of parents and children agreed on the child levels of vulnerability to		This study raises the differences between adults and child's

Author Year of publication	Aims Objectives	Method Analysis	Participants Sample	Major Findings	Recommendations Limitations	Issues raised for the proposed PhD study
comparison of parents and children. Journal of Child Health Care. 8(4) 279-287	<p>children's perceptions of their own health and whether children could verbalise those perceptions.</p> <p>To examine the relation between parents and children's beliefs about the children's health status</p>	<p>likert scale (revised child Vulnerability Scale)</p> <p>Child interview</p>	<p>suburban area. Children were aged from 3y8mths to 5y 6 months.</p>	<p>illness. Of the children who self-rated as vulnerable, 58.3% had parents who considered them more vulnerable. However for the parents who thought their children vulnerable, only 33.3% of the children shared this assessment.</p>		<p>perceptions of vulnerability.</p> <p>This PhD wishes to explore the Gypsy/Traveller perspective of vulnerability rather than the HCP – is this different?</p>
Houtrouw, S., Carlson, K., 1993. The relationship between Maternal Characteristics, Maternal Vulnerability Beliefs, and Immunization Compliance. Issues in Comprehensive Paediatric Nursing. 16 41-50.	<p>What are the relationships between maternal demographic characteristics and vaccination compliance in children 2 years of age or less? What is the relationship between maternal perceived vulnerability to communicable disease and vaccination</p>	<p>Revised Communicable Disease Perceived Vulnerability Scale (CDPVS). % point likert type scale.</p> <p>Demographic Data Collection Instrument (DDCI) – 10 questions to collect demographic data variables (income, ethnicity,</p>	<p>40 mother – children were randomly selected from a list of births within a 20 month period.</p>	<p>Research question 1 - no statistically significant differences, yet when comparing sub group with highest % compliance to subgroup with lowest % compliance, clinically significant difference noted.</p> <p>Research question 2 - No significant statistical differences noted. Group comparison revealed 60.6% of mothers perceiving vulnerability were compliant, and 9.4% of mother perceiving non vulnerability was compliant.</p>	<p>Trends in the data suggest that mother perception of child's vulnerability to communicable disease may be a predictor of immunization compliance</p> <p>Additional research needs to focus on the development of tools to elicit more precise measurements of vulnerability beliefs.</p>	<p>How tools of vulnerability can be used to examine health choices.</p>

Author Year of publication	Aims Objectives	Method Analysis	Participants Sample	Major Findings	Recommendations Limitations	Issues raised for the proposed PhD study
	compliance in children age 2 years or less?	education level, parity, age, day care used, day care immunisation requirements, healthcare facility hours and ,means of transportation)				
Huta, V., Hawley, L., 2010. Psychological Strengths and Cognitive Vulnerabilities: are they two ends of the same continuum or do they have independent relationships with well-being and ill-being? J Happiness Studies. 11 71-93.	Hypothesized that pre-treatment vulnerabilities would predict degree of depression recovery at post treatment. Expected that strengths to play a predictive role in depression recovery to the degree that recovery represent active movement towards positive well-being.	Psychological strengths were assessed using the transcendence scales of the Values in Action Inventory of Strengths (VIA-AS). Psychological vulnerabilities were assessed using the Dysfunctional Attitudes Scale (DAS) on a 30 min web based survey for sample 1 and questionnaires at first and last therapy session for sample 2.	2 samples Firstly 241 psychologically healthy individuals to compare strengths and vulnerabilities in relation to several positive wellbeing measures. Second sample 54 outpatients	On both samples strengths and vulnerabilities did not appear to be mere opposites. Generally the strengths had stronger and consistent unique relationships with positive wellbeing and vulnerabilities had stronger and more consistent unique relationship with ill being. In many cases strengths and vulnerabilities both had a unique relationship with wellbeing, making incremental contributions to life satisfaction, positive affect, self-esteem and meaning.	To expand on this research to a wider more diverse sample.	Vulnerability is often perceived as the opposite of wellbeing; however it is not as simple as this. Vulnerability may not always be negative but could be linked to aspects of wellbeing. It will be worth seeing of the results of this study align with this conception.

Author Year of publication	Aims Objectives	Method Analysis	Participants Sample	Major Findings	Recommendations Limitations	Issues raised for the proposed PhD study
Little, M., Paul, K., Jordens, C., and Sayers, E-J., 2000. Vulnerability in the narratives of patients and their carers: studies of colorectal cancer. Health. 49(4) 495-510	To compare the value bases that various stakeholders bring to health and medical systems	Narrative Interviews with patients with colorectal cancer, their medical carers and other stakeholders. Immersion/crystallization, thematic analysis	10 patients, 8 clinical carers	Vulnerability is a category of relationship between people and between people and systems. Categories identified included <ul style="list-style-type: none"> • Mutual patient –carers vulnerability • Vulnerability to public opinion • Vulnerability to superordinate systems • Vulnerability to knowledge and information • Vulnerability to peers • Vulnerability to family • Vulnerability to self • Managing vulnerability 		Multiple vulnerabilities exist within the exploration of vulnerability in cancer clients.
Myall, B., Hine, D., Marks, A., Thorsteinsson, E., Brechman-Toussaint, M., Samuels, C., 2009. Assessing Individual Differences in Perceived Vulnerability in Older Adults. Personality and Individual Differences. 46. 8-13.	To develop and validate a new instrument that of the perceived vulnerability scale (PVS)	PVS (22 item scale) State –Trait Anxiety Inventory Perceived stress scale Perceived wellbeing scale – revised Centre for epidemiological studies – Depression scale Sense of	391 volunteers (238 female and 153 male) from a range of urban and rural Australia. Aged 50-90.	The 22 item PVS demonstrated excellent internal consistency and good temporal stability. Concurrent validity was supported by observed relationships between perceived vulnerability, anxiety and stress.	Longitudinal research aimed at developing more comprehensive understanding of causes and consequences of perceived vulnerability. Studies investigating the role of perceived vulnerability as a mediator and moderator of other factors known to elicit stress and undermine wellbeing.	Perceived Vulnerability scale (Quantitative measurement) – copy obtained. How were the different aspects identified to be issues? Do the results of this study support these – it will be interesting to see.

Author Year of publication	Aims Objectives	Method Analysis	Participants Sample	Major Findings	Recommendations Limitations	Issues raised for the proposed PhD study
		Coherence scale Life attitude profile.				
Proot, I., Abu-Saad, H., Crebolder, H., Goldsteen, M., Luker, K., Widdershoven, G., 2003. Vulnerability of Family Caregivers in Terminal Palliative Care at Home; Balancing Between Burden and Capacity. Scandinavian Journal of Caring Science. 17 113-121	Part of a larger study, this element sought to explore the needs and experiences of family members caring for a terminally ill person at home. Study was conducted in the Netherlands	Grounded Theory, Interviews with experts and sensitizing concepts derived from the literature was used to develop an open-ended interview guide. Data analyses using the constant comparative methods as described in grounded theory.	Patients (n=13), family caregivers (n=13), bereaved carers (n=14) and professional caregivers (n=13)	Core category of vulnerability illustrated by a number of factors that increase or decrease vulnerability, such as <ul style="list-style-type: none"> Vulnerability increasing factors including care burden, restricted activities, fear, insecurity, loneliness and lack of support. Vulnerability decreasing factors include continuing previous activities, hope, keeping control, satisfaction, good support. Produced this in a balancing model	Further research in this area is required to generalise the findings, as to, does research in different settings e.g., nursing homes, hospices, prison etc. Study showed that support from informal and professional caregivers was not sufficient. Additional work is needed to examine the education and training if professionals concerning the vulnerable position of families caring for terminally ill.	Model developed identifying vulnerability increasing and decreasing factors – noting that vulnerability is not a static state.
Solveig Iversen, A., Graue, M., Råheim, M., 2013. At the edge of vulnerability – lived experience of parents of children with cerebral palsy going through surgery. Int J Qualitative Stud Health Well-being. 8	To explore the lived experiences of patients of children with cerebral palsy undergoing surgery, as they	Hermeneutic Phenomenology Interviews	12 parents of 9 children with cerebral palsy (8-16 years old)	At the edge of vulnerability – felt dependent upon healthcare staff. Wanted to be involved and teach HC staff about their child's specific needs whilst also wanting to be de-burdened of the responsibility. Establishing trust was essential	Importance of acknowledging the parents vulnerable position as well as that of the child	Similar in exploring lived experience yet used hermeneutic phenomenology.

Author Year of publication	Aims Objectives	Method Analysis	Participants Sample	Major Findings	Recommendations Limitations	Issues raised for the proposed PhD study
1-10.	describe them					
Sørli, V., Torjuul, K., Ross, A., and Kihlgren, M., 2006. Satisfied Patients are also Vulnerable Patients – Narratives from an Acute Care Ward. Journal of Clinical Nursing. 15. 1240-1246.	To illuminate the experience of being a patient and cared for in an acute care ward.	Phenomenologic al Hermeneutical Method.	10 patients aged 32-90	3 themes. <ul style="list-style-type: none"> • The human touch • Compromises • Vulnerability –patients expressed feelings of helplessness, a fear of what is happening, confusion regarding what is going on around them, uncertainty of their diagnosis. 	Some of the clients used in the study may not have fallen into a traditional vulnerable group category yet the experienced feelings of helplessness. Main findings of the study is the need to understand the patients vulnerability in their situation to understand better their satisfaction with their care	The study identifies that people should not be put into homogenous groups and that people experience vulnerability, event thought they may not have fallen into a traditional vulnerable group. This proposed study wishes to build upon this and explore the phenomenon of vulnerability further.

Appendix 2 Literature Review Summary Chart – Gypsy/Travellers Research Papers

Key – Types of research		
Mixed methods	Qualitative	Qualitative

UK Literature

Author Year of publication Title of Article	Aims Objectives	Method Analysis	Participants Sample	Major Findings	Recommendations Limitations	Issues raised for the proposed PhD study
Allen, M., 2012. Domestic Violence within the Irish Travelling Community: The Challenge for Social Work. British Journal of Social Work. 42 870-886	To explore the experience of intimate partner violence (IPV) within this ethnic minority community.	Postal Survey – open ended questions Interviews & Focus Group Qualitative thematic approach	Survey to 94 service providers with 33% response rate 5 participants from TC who had experienced IPV + 15 FG	The cultural values of the group can lock women into the abusive situation. There is sometimes a lack of support from police services, and gaining place at a refuge is challenging as many have policies of only housing only Travellers at a time. Findings closely reflect other research on IPV in other ethnic minority communities	Limited sample	Lack of awareness of Social workers of the cultural context can exacerbate their experiences of vulnerability.
Aranda, K., 2005. Community nurses' talk of equality and the discursive constitution of selves. Journal of Advanced Nursing 51(2) 131-139	Explore how a group of community nurses talked about equal opportunities, anti-discriminatory practice &	Semi Structured Interviews. Discourse Analysis Purposive sample	14 Community Nurses, 14 Practice teachers from HEI in England	<ul style="list-style-type: none"> Practitioner self – linked to professional care and NMC. Intuitive self - equality of care as intrinsic to their practice. Impartial Moral self – linked to the notion of justice regarding 	Need to examine postmodernist discourses of subjectivity, diversity and power. No male nurses interviewed	This research supports the need to explore the impact upon service delivery of values of healthcare staff

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	equality in healthcare.			impartiality, neutrality and assumed objectivity. <ul style="list-style-type: none"> • Partial Moral self – trying to reject dominant impartial positions. • Concealed self – concealing opposing roles, personal values at odds with professional values • Dangerous self – very few acknowledge this 		
Bhopal, K., 2011. 'This is a school, it's not a site': teachers' attitudes towards Gypsy and Traveller pupils in schools in England, UK. British Educational Research Journal 37(3) 465-483	To examine examples of good practice in schools and to explore strategies that would improve educational outcomes for Gypsies and Traveller groups.	Analysed using methods of Grounded Theory	20	Research identified some challenged staff perceived when working with Gypsy/Traveller children such as challenging authority. The study also identified a lack of acceptance of Gypsy/Traveller culture by students, and issues re school attendance. Where there is a school identified as having good practice this does not in itself change the attitudes of some teachers towards Gypsy/Traveller		Identified how cultural differences could lead to perceptions and labelling behaviour as negative or poor.
Bhopal, K. 2011 'What about us?' Gypsies, Travellers and 'White racism' in secondary schools in England. International studies in Sociology of Education. 21(4) 315-329.	Educational experiences of Gypsy/Traveller pupils and their parents	2 Studies (1 st mentioned above and 2 nd exploring aspects of home education contrasted with those attending school. Ethnographic		Reasons for not attending school <ul style="list-style-type: none"> • Racism • Teachers' attitudes towards Gypsy/Traveller pupils 	Identified that whiteness was not a precluding factor for racism. Racism in school not taken seriously.	
Cemlyn, S., 2000.	To examine ways	2 parts	31.5% response	Study identified that difficulties		Importance of not

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Assimilation, control, mediation or advocacy? Social work dilemmas in providing anti-oppressive services for Traveller children and families. Child and Family Social Work. 5 327-341	in which the needs and rights of Traveller children were addressed or not by social services (SS).	Part 1 Survey to all English SSD Part 2 10 interviews	rate 43 participants of which 8 were Travellers, and 3 GT Organisations,	still exist in the relationship between Travellers and SS, Travellers still fear and are suspicious of SS		accessing the group through social care.
Convery, I., O'Brien, V., 2012. Gypsy-Traveller narratives: Making sense of place; a co-ethnography. Narrative Inquiry 22(2) 332-347.	How sense of place may be evident in self-constructed Gypsy/Traveller identity.	Co-ethnography	1	Importance of family Importance of geographical place in shaping sense of self. Horse as symbol of Gypsy/Traveller identity		Importance of interviewing participants in their own homes to aid sense of security.
Dion, X., 2008. Gypsies and Travellers: Cultural influences on health. Community Practitioner 81(6) 31-4.	To explore the ontological experience of what it means to be healthy to a Gypsy/Traveller	Grounded Theory Interviews	12	6 Themes – first one linked to WHO definition of healthy, next 5 more related to Gypsy/Traveller <ul style="list-style-type: none"> • Fatalism • Fatalism, stress and ill health • Children and self-control • Perpetuating beliefs and behaviours • Travelling and health 	Improved training to be provided to all who provide services for Gypsy/Traveller To explore impact of negative perspectives on health of Gypsy/Traveller	Importance of developing a rapport and trust with members from the community.
McGorrian, C., Frazer, K., Daly, L., Moore, R., Turner, J., Sweeney, M., Staines, A., Fitzpatrick, P., Kelleher, C., 2012. The healthcare experiences of Travellers compared to the general population: the All-Ireland Traveller Health Study. Journal	To investigate Traveller health service utilization and experiences of health service quality.	Community based census survey		Higher usage of hospital services including emergency room and mental health services. Described poorer quality healthcare experiences.	Focus on communication and engagement with the Traveller population is required in order to address their health needs	Whilst the study highlighted a difference it did not explore why

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Health Service Research Policy 17(3) 173-180.						
Meek, R., 2007. The experiences of a young Gypsy-Traveller in the transition from custody to community: An interpretative phenomenological analysis. <i>Legal and Criminal Psychology</i> 12, 133-147.	Explore the participant's experience of serving a sentence in a young offender institute and the transition from custody back into the community.	Interpretative Phenomenological Analysis	1	Issues of culture and identity are important when seeking to understand experience of GT in custody. Tension between perceived autonomy and role of social factors	Practical social and psychological needs need to be taken into account.	Used IPA
Myers, M., McGhee, D., Bhopal, K., 2010. At the crossroads: Gypsy and Traveller parents' perceptions of education, protection and social change. <i>Race Ethnicity and Education</i> . 13(4) 533-548.	To explore G/T parents' expectations, attitudes and concerns about their children's curriculum	Semi structured interviews	4 Travellers education Service practitioners 10 parents	Themes included <ul style="list-style-type: none"> The place of Gypsy and Traveller education in a changing world Anxiety, safety and the transition to secondary school 	Identified some tensions related to transition from primary to secondary school.	Cultural differences between G/T and settled community
Papadopoulos, I., Lay, M., 2007. The health promotion needs and preferences of Gypsy Travellers in Wales. <i>Diversity in Health and Social Care</i> 4, 167-176.	To ascertain the health promotion experiences needs and references of Gypsy/Travellers.	Focus Group NUD*IST qualitative data analysis package	18 Gypsy Travellers (15F, 3M)	<ul style="list-style-type: none"> Health promotion needs - related to poverty, environmental factors, lifestyle, lack of information and poor access to healthcare and culturally related HP needs Barriers to HP – Poor access to HP, racial discrimination, cultural barriers Preferred HP practices – location of HP (on sites), health promotion media 	More women, on authorised sites	Important to recognise and respect cultural traditions

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				such as leaflets, delivery – health visitors seen as important.		
Powell, R., 2010. Gypsy-Travellers and Welfare Professional Discourse: On Individualization and Social Integration. Antipode 43(2) 471-493		Interviews	26 Welfare Professionals	<ul style="list-style-type: none"> Distance between childhood and adulthood – smaller in Gypsy/Traveller community. Group Identity as an Impediment to “Aspiration” focussing on differing socialisation process away from formal education centred on extended family. The “problem” of social integration – losing of Gypsy/Traveller culture 		
Parry, G., Van Cleemput, P., Peters, J., Walters, S., Thomas, K., Cooper, C., 2007. Health status of Gypsies and Travellers in England. Journal of Epidemiol Community Health 61, 198-204.	To provide first valid and reliable estimate of the health status of Gypsy/Traveller in England	Epidemiological Survey	GT of UK or Irish Origin (n=293) and age-sex-matched comparison sample (n=260) non Gypsy/Traveller	GT reported poorer health status for the last year, more likely to have long-term illness, health problem or disability which limits ADL, more problems with mobility, self-care, pain or discomfort and anxiety and depression was higher. Higher incidents of chest pain, respiratory problems, arthritis, miscarriage and premature death.	Representativeness of sample. Unable to access accurately the socioeconomic status of population. Used self-reporting measures so potential for over reporting	Clear poorer health than matched settled counterparts and implications for vulnerability.
Pinkey, K., 2012. The practice and attitudes of Gypsy and Travellers women towards early infant feeding. Community Practitioner. 85(7) 26-29.	Explored early infant feeding practice of GT women and their attitudes towards breast and	2 questionnaires Questionnaire to GT was presented face to face	53 health visitors (HV)(100% return rate) 20 Gypsy/Traveller	HV survey – 93% at birth were formula fed, 3% breastfed and 4% unknown. At 6-8 weeks 96% of children were formula fed, 0% breastfed and 4% unknown	Small scale study	Low literacy levels required questionnaire to be read out

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	formula feeding.	Descriptive statistics	women			
Smith, D., Ruston, A., 2013. 'If you feel that nobody wants you you'll withdrawal into your own': Gypsies/Travellers, networks and healthcare utilisation. <i>Sociology of Health & Illness</i> 35(8) 1196-1210.	Explore wider structural and institutional context and the influence these contexts play in shaping health beliefs.	In depth interviews and thematic analysis	39 Gypsy/Traveller	<ul style="list-style-type: none"> • Networks; Proximity and health - importance of family. • Discrimination, social closure and use of health services – participants experienced discrimination from healthcare staff and therefore did not use services 		Impact on engagement and recruitment??
Van Cleemput, P., Parry, G., Thomas, K., Peters, J., Cooper, C., 2007. Health-related beliefs and experiences of Gypsies and Travellers: A qualitative study. <i>Journal of Epidemiol Community Health</i> 61, 205-210.	To illuminate findings of the survey of health stays of GT by exploring their health related beliefs and experiences.	In depth Interviews using framework analysis	27 Gypsy/Traveller	<p>Experiences of poor health and daily encounters of ill health normalised and accepted. 4 Themes emerged</p> <ul style="list-style-type: none"> • The traveling Way • Low expectations of health • Self-reliance and staying in control • Fatalism and fear of death. 	Culturally appropriate and sensitive services are required to improve the health experience of GT	Identified practical difficulties in accessing this group
Van Hout, M., 2010. Traveller health and primary care in Ireland: a consultative forum. <i>Community Practitioner</i> 83(5) 27-30.	Reports on pilot study exploring factors that affect Traveller health and experiences of primary care services.	Focus Group Thematic Analysis	13 Traveller Health Unit Stakeholders (6 of which were Gypsy/Traveller)	<p>Themes;</p> <ul style="list-style-type: none"> • Emerging Issues • Recognition of culture and identity • Uptake of primary care services • Role of the Primary Healthcare Team Worker 	Establishment of analysis of local GT needs Improved health records Partnerships Bridging initiatives to ease access of GT to Primary Care Mandatory cultural and racism awareness training for all primary care staff.	? Why not interview GT rather than stakeholders (although some of which were GT)
Van Hout, M., 2010. Travellers and Substance Use – Implications for	To yield an anecdotal presentation of	Semi Structured Interviews	45 providers	Findings indicated that drug and alcohol use in the Traveller community in Ireland is	Vital to consider the needs of Travellers and their reported substance	

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Service Provision. International Journal of Health Promotion & Education. 48(2) 36-41.	Traveller substance use from the perspectives of drug, social, law and community service providers in Ireland.			increasing in terms of excessive alcohol use and patterns of problematic substance use. Travellers have poor awareness of risk and reported to be difficult to engage with.	use in development of drug prevention and treatment protocols	
Van Hout, M., 2011. Assimilation, habitus and drug use among Irish Travellers. Critical Public Health 21(2) 203-220.	To explore assimilation process within the context of Travellers habitus and heightened drug activity.	Focus groups - narratives Content and thematic analysis	57 Gypsy/Traveller	Themes Assimilation and exposure to drugs in the Traveller community – a new pavee? Assimilation can contribute to loss of ethnic identity, fragmentation of traditional norms and cultures posing risk for drug use.		Initial difficulties in accessing participants due to suspicion

Non UK Literature

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Amirkhanian, Y., Kelly, J., Kabakchieva, E., Antonova, R., Vassileva, S., DiFranceisco, W., McAuliffe, T., Vassilev, B., Petrova, E., Khoursine, R., 2013. High-Risk	To examine HIV risk in 6 Roma male sociocentric networks	Interviews	405 men	High Risk behaviours were common (over 57% of men had multiple partners in last 3 months, over 1/3 reported both male and female partners in last year, condom use was low). The participants did not identify	HIV prevention interventions directed towards high risk social networks of Roma re needed.	

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Sexual Behaviour, HIV/STD Prevalence and Risk Predictors in the Young Social Networks of Young Roma (Gypsy) Men in Bulgaria. J Immigrant Minority Health 15, 172-181.				themselves as bi sexual or gay and this was largely due to selling themselves for money due to poverty.		
Bodner, A., Leininger, M., 1992. Transcultural Nursing Care Values, Beliefs and Practices of American (USA) Gypsies. Journal of Transcultural Nursing 4(1) 17-28.		Ethnonursing research method Participant observations and interviews. Analysed using phases of ethnonursing analysis for qualitative data	9 key 20 general participants	Explored emic and etic world view 4 themes <ul style="list-style-type: none"> Marked dichotomy between the Gypsy and Gadge world that limits caring expressions, practices and survival Sacred (spiritual and religious) world is valued whereas world of Gadge is to be questioned and devalued Gypsy world view, social structure provide moral guidance Specific cultural values and care means were evident to protected and maintain Gypsy Life ways. 		Verbal consent better than written consent. Initial mistrust of the researcher
Colombini, M., Rechel, B., and Mayhew, S., 2012. Access of Roma to sexual and reproductive health services: Qualitative findings from Albania, Bulgaria and Macedonia. Global Public Health 7(5) 522-534.	To explore access of Roma in South-Eastern Europe to sexual and reproductive health services.	Focus Groups and thematic analysis	58	5 themes <ul style="list-style-type: none"> Financial barriers and lack of financial resources Requests for informal payments Physical access and geographical barriers Sociocultural issues, racial discrimination and gender 	Low participants numbers Focussed on specific countries	

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				inequalities <ul style="list-style-type: none"> • Low information and awareness levels. 		
Cook, B., Ferris Wayne, G., Valentine, A., Lessios, A., Yeh, E., 2013. Revisiting the evidence on health and healthcare disparities among the Roma: A systematic review 2003-2012. International Journal Public Health 58, 885-911.	To conduct a systematic review of the epidemiological and health service utilization literature related to the Roma population between 2003-2012.			Evidence for lower self-reported health and significantly higher mortality rate for Roma compared to non Roma, greater prevalence of health risk factors for Roma children including environmental risks, low birth weight and lower vaccination coverage. Barrier to care include lack of documentation and affordability of care.	Only looked at quantitative studies More studies on healthcare utilisation is needed	Evident lower health experiences of this community and would this affect their perceptions of their vulnerability.
Dumitras, S., Gramma, R., Roman, G., Parvu, A., Enache, M., Moisa, S., Ioan, B., 2013. Considerations on the particularities of the illness and death perception for Roma people. Revists Română De Pediatrie LXII (1) 69-73.	To identify the perception of disease and death in Rroma traditional communities.	Phenomenological Interviews	23 in Lasi and 25 in Cluj County.	Disease is interpreted as a punishment from God or as a curse, belief that all life's events are predetermined and inevitable. Disease is often associated with shame, representing spiritual and moral impurity. Roma's know or have intuition regarding real risk factors for illnesses.		
Eklund Karlsson, L., Crondahl, K., Sunnemark, F., Andersson, Å., 2013. The Meaning of Health, Well-Being and Quality of Life Perceived by Roma People in West Sweden. Societies 3, 243-260.		Qualitative interviews analysed using phenomenological hermeneutic approach.	33 participants (n=16 women and n=17 men)	Respondents mainly understood concept of health as being healthy and feeling good. Elements that were crucial to this were being employed, having an education, social support from family and friends, freedom and security and the extent of involvement in society.	Some limitations die to potential power differentials of Roma and non Roma interviewer	Identified that research on Roma people own perception of health is scare. Some challenges accessing community due to

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						mistrust – gate keepers helped. Issues re insider and outsider also relevant to my study
Flecha, A., 2013. Healthier Lives for European Minority Groups: School and Healthcare, Lessons from Roma. International Journal Environment Research Public Health 10, 3089-3111.	To identify educational strategies that either contributes to social cohesion or lead to social exclusion.	Case studies of successful schools. 4 year longitudinal case study. Communicative Methodology.	26 case studies in differing European Countries.	Results <ul style="list-style-type: none"> Roma Cultural Values as Assets: Improving Health through Educative Participation (Involving family members in education) Increased Emotional Wellbeing through Educative Participation (Family participation in school increased those individuals feelings of welling) Raising Awareness about Health Issues Caring for Families health Caring for health of the Extended Roma Community 	Need for researchers to include the voices and cultural strengths of the Roma and other vulnerable cultural and ethnic groups when designing educational interventions that aim to improve their health condition.	Hearing the community voice is really important.
Horvai, A., 2010. Recognising the Roma and their Rights: an analysis of exclusion and Integration in the education system. Research in Comparative and International Education 5(4) 394-407.		Semi Structured Interviews Thematic Analysis	Not specified	3 problem categories emerged <ul style="list-style-type: none"> Individual, school system political signifying need for multi layered approach		Did not speak to GT themselves
Janevic, T., Sripad, P., Bradley, E., Dimitrievska, V., 2011. "There's no kind		Focus Groups & Interviews	71 Romani Women	3 levels of racism <ul style="list-style-type: none"> Institutional Racism Personally mediated racism 	Did not compare data to non-Romani women	Chose FG to include women's voices in the

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of respect here” A qualitative study of racism and access to maternal healthcare among Romani women in the Balkans. International Journal for Equity in Health 10, 53-65		Constant Comparison method of qualitative data analysis.	8 Interviews with gynaecologists 11 interview key informants from governmental institutions.	<ul style="list-style-type: none"> Internalised racism 		research process
Kelly, J., Amir Khanian, Y., Kabakchieva, E., Vassileva, S., McAuliffe, T., DiFranceisco, W., Antonova, R., Petrova, E., Vassilev, B., Khoursine, R., Dimitrov, B., 2006. Prevention of HIV and sexually transmitted diseases in high risk social networks of young Roma (Gypsy) men in Bulgaria: randomised controlled trial. British Medical Journal 333, 1098-1011	To determine the effects of a behavioural intervention for prevention of HIV and sexually transmitted diseases that identified, trained and engaged leaders of Roma Gypsy men’s social networks to counsel their own network members	RCT	286 Roma men from 52 social networks	Reported prevalence of unprotected intercourse in the intervention group fell more than control group (81% and 80% at baseline to 65% and 75% at three months and 71% and 86% at 12 months).	Endorsement and advice on HIV prevention from leader of a social network produces change in the reported sexual practices of that network. Limitations included single site and studies with larger samples needed.	Importance of engaging leaders of the community in study.
Kelly, J., Amir Khanian, Y., Kabakchieva, E., Csepe, P., Seal, D., Antonova, R., Mihaylov, A., Gyukits, G., 2004. Gender role and HIV sexual risk vulnerability of Roma (Gypsies) men and	To examine sexual partners, sexual practices and interactions between types of partners and types of sexual practices	In-depth Interviews Thematic Analysis	42 Roma	4 themes <ul style="list-style-type: none"> Greater sexual freedom and acceptance of extra dyadic partnerships for Roma men – whether married or unmarried Impoverishment and lack of sensuality that characterised primary marital relationships 	Study located to a limited number of neighbourhoods. Additional research with larger numbers required Highlights social and	Awareness of gender differentials. Importance of both being aware of and respecting cultural differences within this

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women in Bulgaria and Hungary: an ethnographic study. AIDS CARE 11(0) 231-246.	among Roma men and women, assess behaviours and attitudes concerning use of sexual protection and characterise knowledge and beliefs about HIV/AIDS, explore sexual communication patterns within and outside sexual partnerships			sexual lives of Roma men and women <ul style="list-style-type: none"> Diverse and often taboo sexual practices that occur within Roma men's contacts with casual and extra dyadic partners Men's abusive and coercive treatment of female sexual partners, 	contextual issues related to sexual HIV risk among Roma and need for HIV prevention programmes for this population.	community
Kolarcik, P., Madarasova Geckova, A., Reijneveld, S., Dijk, J., 2012. Social Support, hopelessness and life satisfaction among Roma and non Roma adolescents in Slovakia. International Journal Public Health 57, 905-913.	Compare social support, life satisfaction and hopelessness of Slovak Roma and non Roma adolescents and to assess impact of parental education and social desirability on these differences.	Mixed methods Interviews and questionnaire	330 Roma and 722 non Roma	Roma adolescents reported higher social support from parents, higher life satisfaction and higher hopelessness rates.	Limitations related to different ways of collecting data (interviews for Roma and questionnaire non Roma) Need to address hopelessness of Roma adolescents as can be risks for depression in later life.	That hopelessness and higher life satisfaction occurred simultaneously
Kósa, K., Daragó, L.,		Environmental	3145	758 colonies were identified with		

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Ádány, R., 2009. Environmental survey of segregated habitats of Roma in Hungary: a way to be empowering and reliable in minority research. European Journal of Public Health 21(4) 463-468.		survey of all settlement in Hungary		approx. 134000 inhabitants. 94% of all colonies were populated predominantly by Roma. Environmental problems included lack of sewage and gas mains, garbage deposits, waterlogged soil and lack of water mains.		
Masseria, C., Mladovsky, P., Hernández-Quevedo, C., 2010. The socio-economic determinants of the health status of Roma in comparison with non-Roma in Bulgaria, Hungary and Romania. European Journal of Public Health 29(5) 549-554.	Identifying the determinates of health status among Roma in comparison with non-Roma in Bulgaria, Romania and Hungary	Non Linear models Data set from United National Development Programme	2536 for Bulgaria, 2640 for Hungary, and 3292 for Romania.	Roma were significantly more likely to report worse health in any indicator that non-Roma		Worth exploring these results alongside other studies in the UK re Health outcomes.
Melgar, P., Larena, R., Ruiz, L., Rammel, S., 2011. How to move from Power-based to Dialogic Relations? Lessons from Roma women. European Journal of Education 46(2) 119-227.	Analyse communities involved in learning projects which help to reduce or prevent inequality and marginalisation and promote social inclusion and empowerment.	6 longitudinal qualitative case studies	318 surveys, 29 semi structured interviews, 47 communicative stories, 19 professional communicative discussion 10 communicative observations	Data gathered on INCLUDE-ED project. Findings <ul style="list-style-type: none"> Building dialogic relations in school including demonopolisation of the expert knowledge, and recognising Roma culture Benefits of Dialogic relations 	Importance of working together to enact change	Partnerships
Monasta, L., Andersson,	To test methods	Community based	5 settlements –	In 15 days prior to survey 32% of	Research should be	At times difficulty

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N., Ledogar, R., Theol, D., Cockcroft, A., 2008. Minority Health and Small Numbers Epidemiology: A case study of living conditions and the health of children in 5 Foreign Roma camps in Italy. American Journal of Public Health 98(11) 2035-2041	of generating epidemiological evidence in health conditions of small dispersed minority communities.	mixed methods	15 families	children suffered diarrhoea, 55% had cough. Risk factors linked to years spent in camp, overcrowding housing conditions, use of wood burning stoves, presence of rats and quality of sanitation and drains.	driven by people priorities and designed to include their perception and point of view.	in engagement due to other prioritising demands. Importance of the research being driven by participants
Pantea, M., 2012. From 'Making a Living' to 'Getting head': Roma women's experiences of migration. Journal of Ethnic and Migration Studies 38(8) 1251-1268.	Examine the way in which Roma migrant women experience migration.	Semi structured interviews	6 communities in Transylvania	Roma women's migration is highly dependent on the gender regime in their home communities.	Recognition not a homogenous group but multiple sub groups	
Pășcuță, A., 2012. Violence in Gypsy Families. Revista de Asistență Socială, anul XI (4) 113-120.	To capture, understand and highlight violence from Gypsy families	Semi Structured Interviews	20	Violence towards women is not isolated towards Gypsy culture. Yet there are cultural aspects such as <ul style="list-style-type: none"> • Some act are not perceived as violent by women • Privileged place of men in the community • Little information to Gypsy women on their rights • Neighbours friends and family try to limit the extend of the violence • Poor response by police 		Be aware of my own personal beliefs regarding women and ensure these to do interfere with the research
Rechel, B., Blackburn, C., Spencer, N., Rechel, B., 2009. Access to	Access to child health services in Bulgaria	Qualitative In-depth interviews Thematic Analysis	50 (healthcare providers working with children	Findings Poverty, Geographical barriers, low levels of education, Administrative	Project to improve Roma health include training of health	Importance of culture and recognising

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healthcare for Roma children in Central and Eastern Europe: findings from a qualitative study in Bulgaria. International Journal for Equity in Health. 8, 24			n=13, users of health services n=12, policy makers n= 10, other stakeholders n= 15)	barriers, healthcare reforms, discrimination, cultural differences	mediators, training of healthcare workers. Need to ensure access to services to improve health.	cultural differences between myself as researcher and the participants.
Roman, G., Gramma, R., Enache, A., Pârvu, A., Loan, B., Moisa, Ș., Dumitraș, S., Chirița, R., 2014. Dying and Death in some Roma Communities: Ethical Challenges. Journal Immigrant Minority Health 16, 290-300	To examine self-described behaviours and practices, their experiences and perceptions of illness, death and dying.	Semi structured interviews	48	5 Themes <ul style="list-style-type: none"> • Perception of illness in the community as reason for and isolates that results from this • Importance of family as major support for dying individual, including social requirement that family with gather when someone is dying • Belief that patient should not be told their diagnosis and family should be main decision makers regarding medical treatment • Reluctant to decide on life prolonging treatment • View of death as impure. shame 	Increased cultural awareness for staff. Methodological limitations as qualitative interviews Can be conflicts in cultural beliefs of Roma with westernised healthcare.	
Pavlič, D., Zelko, E., Kersnik, J., Lolič, V., 2011. Health beliefs and practices among Slovenian Roma and their response to febrile illnesses: a qualitative study. Zdrav Var 50, 169-174.	Investigating health beliefs and practices held by Roma in Slovenia and their response to febrile illness.	Semi structured questionnaire that was verbally presented to participants	136 Roma (n=88 women and n=48 men)	Perceptions of health included good diet, sound sleep, normal breathing, and absence of pain, shaking limbs and tingling. Majority so not take temperature when feel ill as most do not have a thermometer. Only 28% knew normal body temperature , used traditional remedies for reducing		

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				fever (tea, grated potatoes or cold compress)		
Rosário, P., Núñez, J., Azevedo, R., Cunha, J., Pereira, A., Mourão, R., 2014. Understanding Gypsy children's conceptions of learning: A phenomenographic study. School Psychology International 35, 152-166.	To explore the way Gypsy children think about learning	Phenomenographic	26 Portuguese Gypsy children	Perceived basic numeracy and literacy skills as important to help their families sell at fairs. Children indicated they do not intend to continue studying beyond elementary school as they believe learning these basic skills is enough for living ad a Gypsy	Methodological limitations Essential to work with families to reinforce value of learning and attending school, also to sensitive teachers and provide them with information re Gypsy culture.	
Vukovic, D., Nagorni-Obradovic, N., 2011. Knowledge and awareness of tuberculosis among Roma population in Belgrade: a qualitative study. BMC Infectious Diseases 11 284-292.	Knowledge and belief about transmissions, symptoms and treatment to TB as well as attitudes towards patients with TB among Roma population in Belgrade.	Focus Group	24 Roma people	All participants knew TB was a pulmonary disease and contagious. Some participants felt could be transmitted through handshaking although most identified it was through saliva. Other factors included bad living conditions, lack of food and stress. Effective treatment included taking medications, inhaling fresh air, eating strong food (bacon and pork) and traditional remedied.	Importance of providing outreach activities and promote knowledge of TB	

Appendix 3 Consent Form

Consent Form

Study Title: "The Lived Experience of Vulnerability". Understanding vulnerability of a Gypsy/Travelling community:

Researcher: Vanessa Heaslip

Please **initial** boxes

1. I confirm that I have read or have had read to me the participant information sheet (Version 1 Dated: 15th Feb 2010) for the above study. I have been able to ask questions and have had these answered.

2. I understand that my involvement is voluntary and that I am free to withdraw at any point without giving a reason, and have the choice to have any taped interviews destroyed.

3. I agree to the interview being tape recorded, and understand that the tape will only be heard by the researcher and the researchers' supervisors.

4. I understand that parts of my story may be used in the researchers dissertation or in research papers. When parts of my story are used these will be anonymised and I will not be identified.

5. I accept that the researcher will keep the tape recording of our interview until the study has been completed and then it will be destroyed. The tape will be destroyed in accordance with Data Protection and Records Management Code of Practice (DH 2006).

6. I agree to take part in the above study

Name of Participant Date Signature

Person Taking Consent Date Signature

Appendix 4 Participant Information Sheet (initial)

STUDY TITLE: "The Lived Experience of Vulnerability". Understanding healthcare vulnerability from a Gypsy/Travelling community perspective.

Invitation

You are being invited to participate in a research study being carried out as part of a programme of study. Before you can decide if you wish to be involved it is important to understand why the research is being carried out. Please read the following information and discuss it with others if you wish. If you have any questions, please feel free to ask the researcher directly, or contact them at a later date (contact details are at the end of this information sheet).

Purpose of research

Whilst much has been written about vulnerability and the Gypsy/Travelling Community, this is largely written from the professionals (nurses, doctors, social workers) point of view.

What is missing, and what this research hopes to explore is the voices of the individuals who have experienced feeling vulnerable within the community themselves.

Why have I been invited to participate?

You have been chosen to be involved as you have identified that when thinking about your health, you have experienced feeling threatened or felt a fear of harm.

What will happen if I take part?

If you decide to be involved in this study then you will be invited to share your story with me in a one-to-one interview. The interview may last up to one and a half hours and will occur in a place where you feel comfortable.

How will the information you share be used?

Your story will only be used for research purposes. If you decide to take part I will ask your permission to tape the interview. Any information taken from these

interviews will be anonymised so no one (apart from me) will know who said what. All information you share with me will be kept strictly confidential with data stored on password protected computers in accordance with data protection rules. The results of the research may be printed in relevant journals and at conference presentations.

What are the possible disadvantages and benefits of taking part?

We do not expect participation in this study to cause you any significant risk or harm. You may find that you benefit from taking part in the interviews, having the opportunity to have your voice heard. Being involved in the research is entirely **voluntary**; as such you have the right to decide what stories you choose to share. You may also withdraw from the study at any time and doing so does not affect your legal rights.

What do I have to do?

If you wish to be involved, speak to Vanessa who will arrange a day and time to meet with you.

Contact Details

Vanessa Heaslip
Senior Lecturer Adult Nursing
School of Health and Social Care
2nd Floor Bournemouth House
Bournemouth BH1 3LT
Tel: 01202 961774

Thank you for considering to take part in this research study.

Appendix 5 Initial Feedback from the Research Governance Review Group

School of Health and Social Care - Research Governance Review Group

Feedback to student and supervisors

Student: Vanessa Heaslip

Title "The Lived Experience of Vulnerability". Understanding healthcare vulnerability from a Gypsy/Travelling community: using a holistic healthcare perspective.

Reviewers: Ann Hemingway; Martin Hind Report prepared by: Martin Hind

Date: 24.03.10

Dear Vanessa

Thank you for submitting your interesting study to the research governance review group (RG2). Before you proceed with your study some issues around the content of the Participant Information Sheet (PIS) and consent form have been raised by this review which will require your attention.

- 1) Participant information sheet/ consent form
 - a) The supplied PIS is well written and very informative but the review identified potential issues around understanding of some terms in respect of your intended sample. E.g. 'program of study' and the term 'vulnerability' might need explaining in more lay terms. It was also felt that including the term 'vulnerability', which is a complex term, might be off-putting to potential participants. Please re-review your PIS and where possible simplify terms and re-consider how you introduce the notion of vulnerability to potential participants.
 - b) Please add one of your supervision team as an alternate contact on the PIS (this is necessary in case a participant has a concern which they feel they cannot raise with you).
 - c) You should state how long you intend to keep data (within your data protection considerations).
 - d) You should indicate how many participants you will be seeking to recruit; A rough range is sufficient as it is appreciated that the exact sample size often is not determined until data collection commences. This will also serve to inform participants that other members of their community will be involved in the study.

That concludes the points raised by the RG2 review, please consider all of these points with your supervisory team and respond to us at RG2@bournemouth.ac.uk with only your revised PIS and consent form, as indicated in this report.

Appendix 6 Response to Research Governance Review

26th April 2010.

Dear Ann and Martin (Reviewers for RG2)

Thank you for the comments you kindly provided on my RG2 submission. Upon reviewing your comments please find included the new version of the PIS form.

Specifically I have

1. Added my first supervisor as a point of contact. I agree that it is important the participants are able to access someone else, in case they have a concern they feel they cannot raise with me.
2. I have added to the PIS that I will keep the information for 5 years in light of research governance expectations. I apologise for this oversight.
3. I have also identified within the PIS that I am wishing to recruit up to 8 participants.
4. Lastly I have reviewed the language used and tried to ensure that I have simplified terms, especially in light of the poor literacy of some members of the community. In addition I have also spoken to some contacts within the faith community regarding these concerns. They have acknowledged these and advised that as long as I clarify any words used when verbally reading out the participant information sheet they do not perceive there will be a problem.
5. Your guidance suggested that I consider defining vulnerability in more lay terms. I have tried to do this, however this is difficult to achieve without unduly influencing the stories and experiences shared by the community. I have re written the dictionary definitions of vulnerability into more lay terms however I do not wish to prejudice their thoughts by providing a normative healthcare perspective of vulnerability. A study by Leroux (2005) used the same approach of descriptive phenomenology to understand the lived experience of vulnerability in psychotherapy and I have used this study to assist me in clarifying the term vulnerability as this study did not experience any difficulties in the participants understanding the term. I hope you find the new explanation more participant friendly. However I do plan to pilot the interview before data collection commences so this will enable me to identify if further amendment would be required.

I hope this addresses the concerns raised

Yours Faithfully

Vanessa

(Vanessa Heaslip)

Appendix 7 Participant Information Sheet (revised)

Participant Information Sheet

Study Title: "The Lived Experience of Vulnerability". Understanding vulnerability of a Gypsy/Travelling community:

Invitation

You are invited to be involved in a research study carried out as part of a university course. Before you decide if you wish to be involved, it is important to understand why the research is being carried out. Please read the following information and discuss it with others if you wish. If you have any questions, please feel free to ask the researcher or research supervisor directly, or contact them at a later date (contact details are at the end of this information sheet).

Purpose of research

I am interested in people's experiences of vulnerability. All individuals can experience vulnerability at some point in their lives. Whilst much has been written about vulnerability and the Gypsy/Travelling community, this is largely written from the professionals' (nurses, doctors, social workers) points of view. What is missing, and what this research wishes to explore are the voices of the individuals themselves who have experienced feeling vulnerable. This side of the story is important to ensure that the professionals (nurses, doctors, social workers) working with people who are experiencing vulnerability, have an understanding of what vulnerability means in order to be able to provide more appropriate care .

Why have I been invited to participate?

You have been chosen to be involved as you have said that you have experienced feeling vulnerable and I am interested in hearing your experiences.

What will happen if I take part?

Initially, I would like to talk to individuals who have experienced feeling vulnerable and hear those experiences. If they are willing, I would then like to meet with them again in order to examine a few of those experiences in greater depth. In total I am hoping to talk to about six to eight people and hope that you agree to be one of them. If you are willing to talk to me about your experiences of vulnerability I will ask you to share your story with me in a one to one chat which may last up to one and a half hours. This chat will take place in an area of your choosing (for example your home, local community centre).

How will the information you share be used?

Your story will only be used for research purposes. If you decide to take part I will ask your permission to tape record the interview which will be downloaded on to a Bournemouth University laptop. Any personal data (such as your name) will be anonymised and all identifiable information will be removed so no one (apart from me) will know who said what. All information you share with me will be kept strictly confidential with data stored on password protected computers. All paper based data will be stored in a locked cupboard and stored within Bournemouth University for 5 years, in accordance with the university's research regulations. The results of the research may be published in relevant journals and at conference presentations in order to share your experiences, however when I use examples these will be anonymised.

Who has approved the project?

This research has been approved by the Health and Social Care School's Research Governance Group at Bournemouth University.

What are the possible disadvantages and benefits of taking part?

I do not expect participation in this study to cause you any significant risk or harm. You may find that you benefit from taking part in the interviews, through having the opportunity to have your voice heard. Being involved in the research is entirely **voluntary**; as such you have the right to decide what stories you choose to share. You may also withdraw from the study at any time, if you choose to do this then all information about you will be removed from the study and destroyed. This does not affect your legal rights.

What do I have to do?

If you wish to be involved, speak to Vanessa who will arrange and day and time to meet with you.

Contact Details

Vanessa Heaslip
Senior Lecturer Adult Nursing
School of Health and Social Care
2nd Floor Bournemouth House
Bournemouth BH1 3LT
Tel: 01202 961774

Dr Sarah Hean
PhD Supervisor
School of Health and Social Care
1st Floor Royal London House
Bournemouth BH1 3LT
Tel: 01202 962201

Thank you for considering taking part in this research study.

Appendix 8 Research Governance Review Approval



School of Health and Social Care

Research Governance Review Group

Feedback to student and supervisors

Student: Vanessa Heaslip

Title "The Lived Experience of Vulnerability". Understanding healthcare vulnerability from a Gypsy/Travelling community: using a holistic healthcare perspective.

Reviewers: Ann Hemingway; Martin Hind

Report prepared by: Martin Hind

Date: 28.04.10

Dear Vanessa

Thank you for re-submitting your study to the research governance review group (RG2) in light of your original review (dated 24.03.10).

Your revision of the participant information sheet and your added comments of clarity have sufficiently addressed issues raised in the original review and so your study is now fully approved to proceed. This approval will be ratified at the School Postgraduate Committee on 5th May 2010. On behalf of the research governance review group I wish you all the very best with your study.

A handwritten signature in black ink, appearing to read 'Eloise Carr'.

Eloise Carr
Chair of School Postgraduate Committee

Appendix 9 IHSRC Presentation

Slide 1

Vanessa Heaslip
PhD Student (PT)/Senior Lecturer

**"The kaleidoscope of vulnerability".
Proposing a methodological approach
enabling breadth and depth of exploration.**

Slide 2

The Beginning



Slide 3

The Etic and Emic debate

Vulnerability (Noun) Etic	<ul style="list-style-type: none">• Susceptibility to & possibility of harm• Externally evaluated/judged description by someone else, normative, dichotomous, homogeneous.• Quantitative measures of health, biomedical, says nothing about what the person might be experiencing
Vulnerable (Adjective) Emic	<ul style="list-style-type: none">• "State of being threatened & feeling/fear of harm"• Internally judged, description of the experience of being/feeling vulnerable.• Qualitative & holistic• Silent in health care literature

(Spiers 2000)

Slide 4

Perspectives of Vulnerability

- Mechanism to identify populations at risk of ill health
- Mechanism, to identify social groups in need of protection
- Consequence of social interaction, influenced by societal values
- Shifting experience
- Existential experience
- Vehicle for personal growth



(Heaslip 2011)

Slide 5

Vulnerability & the Gypsy Travelling Community

MECHANISM TO IDENTIFY POPULATIONS AT RISK OF ILL HEALTH	ACCESS TO HEALTH SERVICES
<ul style="list-style-type: none">▪ Poorer physical health (Goward et al. 2006).▪ Parry et al (2007) poorer health than their age sex matched counterparts, and were significantly more likely to have long term illness, health problems or disability.▪ Poorer Mental health than general population (Goward et al. 2006; Parry et al. 2007).	<ul style="list-style-type: none">▪ Experience difficulties in accessing services due to a lack of realistic & accessible information (Cemlyn 2000b).▪ Peters et al (2009) 69% were permanently registered with a GP.▪ Inadequate information, inequitable & poorly delivered services (Hodgins et al 2006.)

Slide 6

Vulnerability & the Gypsy Travelling Community

CONSEQUENCE OF SOCIAL INTERACTION INFLUENCED BY SOCIETIES VALUES	THE LAST BASTION OF RACISM
<ul style="list-style-type: none">▪ Peternej-Taylor (2005) defines vulnerable populations as those who are typically impoverished, disenfranchised, or who are subject to discrimination, intolerance, and stigma.▪ The Gypsy/Travelling community is recognised as one of the most socially excluded marginalised groups (McCaffery 2009, Van Cleemput et al. 2007)▪ Experience discrimination (Kamer 2004; Turner 2002).▪ Cemlyn (2000a) argues that the travelling community could be perceived as vulnerable due to these structural inequalities experienced, as well as a tendency to pathologise them which reaffirms them as other which results in increasing their vulnerability.	

Slide 7

My Research

"The Lived Experience of Vulnerability".

Understanding vulnerability from a Gypsy/Travelling perspective



Slide 8

The Confusion

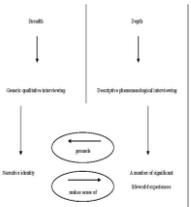


- What is vulnerability?
- Does it mean something different to individuals in the Gypsy/Travelling community as opposed to the normative perspective??
- Do I need to understand the breadth before I can explore the depth?

Slide 9

Breadth & Depth in Qualitative Research (Todres and Galvin 2005)

- Study exploring experiences of caring for a loved one with Alzheimer's disease.
- Two phased methodological approach,
 - Phase 1 - generic qualitative study of narrative breadth in order to generate a broad thematic understanding of the narrative.
 - Phase 2 - in-depth study of particular selected phenomenon chosen from the broad narrative via descriptive phenomenology
- Utilising this approach Todres and Galvin (2005) argue provides an understanding of the breadth of the phenomenon as well as the depth of the experience.



Slide 10

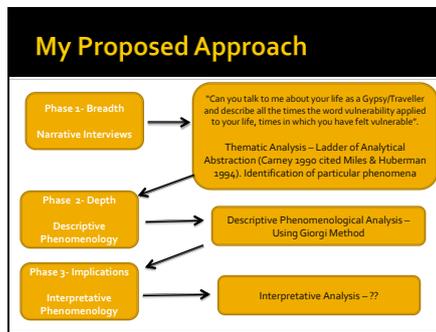
Challenges of this approach to my study

- Greenfield & Home (2006) argue that too often Gypsies/Travellers are over investigated for the purposes of research which fails to bring about clear change; or that the research is carried out in a manner which is either meaningless or potentially offensive.
- This has resulted in the gypsy and travelling community reporting feeling exploited by researchers and academics.



Practice, educational and theoretical implications of the study.

Slide 11



Slide 12



Comments.....

Thoughts.....

Vanessa Heaslip
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vheaslip@bournemouth.ac.uk
Tel: 01202 255326.

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Appendix 10 Contact Summary Form

Contact Summary Form

Contact Type:	Stage 1 face to face interview	Site	Jimmy's Site
Visit	Jimmy	Contact Date	31/10/11
		Today's Date	1/11/11
		Written By	VH

1. Description of contact

Jimmy* aged 59 is an Irish Traveller. He lives with his wife and grown up children on a site which he was given temporary planning permission for and is now fighting for permanent planning permission. He had 8 children (3 sons and 1 daughter lives on his site). He has lived here for 4 years. The site is quite extensive and beautiful with hard landscaped areas. There are small children (Jimmy's grandchildren on the site)

2. What were the main issues or themes that struck you with this contact?

I was amazed to hear how young Jimmy* was, as his physical health and looks I thought that he was much older than he actually was.

Issues arose related to;

Financial vulnerability, vulnerability due to a feeling of not belonging, experienced extreme hostility by the local community. Feels that his culture is being eroded

3. Anything else that struck you as salient, interesting, illuminating, or important in this contact

The amount of love and money that he and his family had installed into their site and that may be taken away from them. If I had not been there before I would never have known there was a site there as you couldn't see it from the main road, how invisible they are.

4. Self-reflection on process what if anything would I do differently?

From Jimmy* I really got a better understanding of the use of language. For example I knew Irish Traveller prefer the term Traveller, and that Romanies prefer the term Gypsy however Jimmy* would refer to them as English Travellers as to him the word Gypsy is associated with negative connotations and is a discriminatory word to use.

Willing to see me again

Stop.

Appendix 11 Contact Summary Form with coded themes

Contact Summary Form with Coded Themes – Jimmy*

Contact Type: Face to Face interview with Jimmy*

Site: Jimmy's Site

Contact Date 31/10/11

Today's Date 14/04/12

Written By VH

Page	Issues	Categories	Themes - descriptions
1-2	They put me into school and that I was..when people first started calling me a Gypsy, because the school where I went was, as I say, 4 or 5 streets away from where we were living in rooms. And that's when they started calling me a Gypsy and smelly and stuff. And I couldn't understand it. I didn't know what a Gypsy was.	Bullying,	School Discrimination
2	The first time it happened I went home and I explained to my father and he explained to me that we were not Gypsies but Travellers. Gypsies is a very bad name to call anyone in our culture. It's basically the worst thing you can say.	Language, labelling	School Discrimination
2	I was in school till I was 14. With the names and the bullying, I just couldn't hack it.	Bullying	School Discrimination
2	Where my cousin was staying there was an old railway track and people all the local people and the few Travellers that were there in the camp where they were, use to pick coal off the railway line. Even all the people out of the houses... So my cousin said to me – you and *** - that's another cousin – go over and get 2 buckets load off the railway – so we went over and there were, let's say, about half a dozen, a couple of adults, they were country people and me and ***. So picking away we were and the next minute a siren comes along, a police van. He takes everyone's name and came to us, told them to go, came to us give them our names and told them where we were from and they said – right you're under arrest. That time it was called larceny this same age it's trespassing.	Treated differently, police	
2	And that was really the really first time I knew the police at that time had all the power to move you on and, and the police had all the full powers to move and so...	Fear of police, lack of control	
3	I really realised that we weren't liked. That we were completely different - different person to what country people were.	Feeling different, not belonging, not	

Page	Issues	Categories	Themes - descriptions
		liked	
3	That time everyone used to help one another. One fella had a fever so he said to my father – did you get on today, no? - So he gave him a couple of quid. So my father would do the exact same so whatever men that were there would do the exact same, so the person that had nothing he would have a wage at the end of the day, but he would have to do the same and vice versa.	Looking out for each other, community	
3	But all of a sudden one morning you would wake up with banging and it would be the police. They didn't care who was in the trailer. Half the time they put the windows through if you wouldn't get up and they wouldn't give you time to take the jacks off. They would just drag the trailers out even if the children were still in bed, they would just drag them out onto the road.	Fear of Police, law, lack of control, not treated as a person	
3	In the 70's then the council took over. And a law came out that had to be one permanent site and one transit site in each town. So like we had to have a permanent and a transit, which it did.	Changing times	Changing times
4	It went through parliament. A law came out that there were only allowed 5 caravans and 5 vehicles in one convoy.	Changing legislation	Changing times
4	Maggie Thatcher and John Major, they came out with a plan to demolish the sites the council had no need to provide sites or whatever and that was how the Traveller people would buy green belt land and it would pass it through 100%. And just save up, 2000 Travellers did buy land. I wouldn't say 10 were passed, the rest was turned down and that's where we are today.	Changing times, legislation, discrimination, lack of equity	Changing times Discrimination
4	This day and age Travellers, you can't travel. You've got to be, well if you go on the side of the road you can have, some councils can have you out within 2 or 3 hours if they've got the manpower to do it but basically its 24 hours. So you are moving all the time.	Loss of identity, erosion of culture	
4	But nearly everyone you go to they say to put down for temporary and that can take maybe a week or so. But in that time, that week while you're waiting to see the doctor you're pulled out. Do you know it's very, very hard to go into the surgery and see a doctor. So basically what we do is we just go to the A & E, the emergency hospitals and the doctor will see you. But they will only see you once - you can't keep going back. You've got to get a GP and if you're on the road it near impossible.	Healthcare vulnerability, access to healthcare, resourcefulness	Healthcare
4	Oh god, I (missing the ability to travel)	Erosion of cultural ways	
5	Nowadays, you go outside and light a fire. You cook your meals on it. It's just so beautiful. You can't, you go down a back road today and pull in on the side of the verge, within half an hour there would be a farmer down. Someone over you, trespass, this and that. Within an hour you've got the police and the next, and virtually its always the next day but sometimes they get you off in a couple of hours and you're	At one with nature, Financial vulnerability, changing times,	

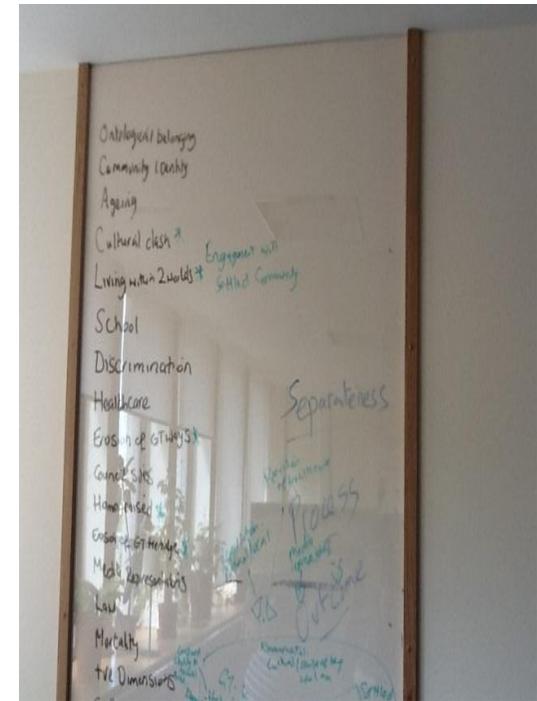
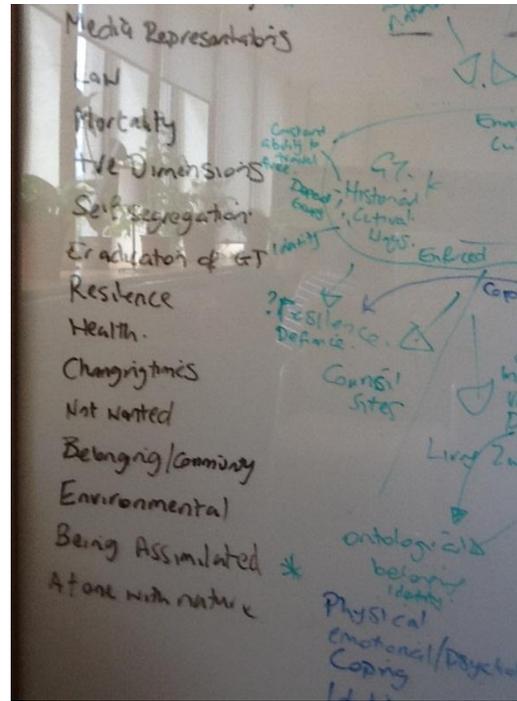
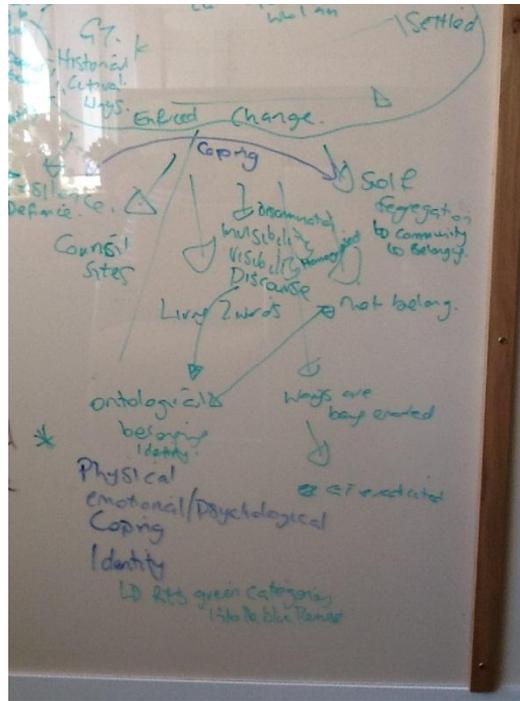
Page	Issues	Categories	Themes - descriptions
	gone. So there is no work.	culture being criminalised	
5	You take it from me, within another 20 years, and in time that's not that long, and you won't see a Traveller on the road it, it's gone.	Erosion of the G/T culture	Eradication of GT ways
5	No matter what government gets in the Traveller is the underdog. He's like, well if he wants to live like that, let him live it, we will make it as hard as we can for im.	Lack of control, not being valued/important	Eradication of GT ways
5	In this day and age now the way that's going on with Travellers and that, I can only see one thing happening, they want to wipe us out...that's what I'm saying You might say that it's going a bit too far, but I'm telling you honestly and a lot lot of people of my culture are thinking the same way.	Ethnic cleansing, being wiped out.	Eradication of GT ways
5	They just can't get their head around the fact, they must think we have come out of space or something, that we are aliens you know what I mean.	Being made to feel different	
5	There is good and bad in Travellers, we are all the same, there's good and bad in the outside world as well.	Stigma with GT, homogenised	
5	And the people keep saying, why are you not paying taxes, well 90% of them are paying taxes. Because now you can't work without being registered, you got to be taxed registered. And this is what a lot of people don't understand.	Misconceptions, stereotypes	
5	The only thing that would bother me about living in a house is the name calling...	Not wanted, name calling	
6	But the biggest majority of them are just against us. I don't know, probably cos we live in a caravan and they live in a house. What difference is that going to make to their life? But they say we'll make his life hell cos they live in a caravan. But if he moves into a house he is ok. But if a Traveller moves into a house, they'll look at them up and down and call them smelly gypo or whatever.	Feeling different, don't belong, being different, stigma	Discrimination
6	I have tried to live in a house. I tried living in a house when my granddaughter was born cos the doctor said that she couldn't live in a caravan cos there was a lot of machines that she had to be on that time. We tried it for 18 months. It was just like - well it was horrible.	Vulnerable living in a house	
6	When we first came here, the meeting up here, there must have been 150 people who went to the meeting were against us they were 100% against us	Not wanted, not valued or accepted	Ontological security
6	Him and my grandson walked out of the gap here to see if there were any mail and that used to be the way in here and they found, I think it was 12 bullets or 15 was it on top of the letter box	Post box being shot at, not belonging, not	Not wanted, discrimination

Page	Issues	Categories	Themes - descriptions
		wanted, physically vulnerable	
7	...sent someone down there, after 2 months. Could have been dead and buried, do you know what I mean, but that was a country person there would be statement cos that was a lot more looking into it.	Treated differently by police, lack of equity.	
7	it's just like bullies that bullied us at school. Even though they were bullying me, I fight back and I fight harder even though I'd lose. Every time I got hit I would hit back and I'd fight and I'd try and fight harder. That's the way with Travellers. If they're put down they'll bounce right back up. We are proud people, very proud. Proud of who we are, proud of where we come from. No matter what the outside world says, no matter what they say they will never be as good as us.	Bullying at school Positive dimensions of vulnerability, resilience	School
7	. For the simple reason is a Traveller is, say a Traveller is in desperate need, say he died, his family has nowhere to go. Even though I don't know that man, we just got to hear about it. Say it's in London, I got nephews in London, and every one of my nephews would go round there and see the people are alright. If they need anything. Get it. That's not only me would do it, that would be every Traveller that would hear about such a thing was happening, they will do it as well.	Community	
8	She's got 4 kids as well so she brought the trailer with her and the council within 2-3 days and gave me a warning in a letter that if she didn't get off, ... if I didn't pull my daughter off they'd take action they'd take the licence or something to do with the licence	Treated different, no control over land.	
8	A little girl she had and the girl was born on New Year's Eve, 2 minutes after 12 on new year's day. And do you know something all the people that have their babies new years day, they take their photograph. I think there were 5 along with my granddaughter, all the other 5 kids, their photographs were in the paper but not my granddaughter.	Not treated the same, being treated different, lack of equity, not valued	Discrimination
9	The council gave us permission to build ..day rooms. Whatever we want and they gave us permission not just to stay here but to build whatever we wanted to do and then when the 3 years were up they rejected the whole lot. So I can't understand that, I just can't make it out. The planning committee they recommended a full licence but it was the parish council, they said no.	Lack of control, not knowing about the future, lack of security	
9	They came down and said we are willing to give you a 3 year licence with planning, would you consider putting a new road in there? I said yes. The wanted me to put it, you see where that pole is, they wanted me to put it from there to there. I just said that that's going to cost us an awful lot more. Wouldn't it be better if – cos the village they're complaining - to put the road right the way down and they said that would be a brilliant idea. So I said yes but even though it cost near enough treble what the small one	Having to go that extra mile, in order to get planning. At own cost	

Page	Issues	Categories	Themes - descriptions
	would have been we done whatever they wanted.		
10	The local bobby, she comes here maybe once every month. I always ask is there any complaints and I make sure that if there is a complaint I can deal with it, but there never is. There's 6 people in that village, 3 blokes and their wives, and their 101% against us	Being checked up on, not accepted.	
10	I asked him what his problem was and he said I just don't like you. He said if you were English I would have no problem with it	racism	Discrimination
11	So, just because I'm an Irish Traveller. I was born in the UK though. My wife was born in the UK. All my kids and grandkids were born in the UK. I wouldn't say any of my kids have been in Ireland in all their life for more than 24 hours.	British citizen	
12	The electric, well the boys wanted to turn that on ages ago but I always had a niggly thorn under my mind.	No electric mains	
12	Every site you go on there's nothing but trouble, there's always arguments cos you're close together. You are like cattle in pens, big and small pitches you're on top of one another. Travellers are meant to have space that's why you look out here it's all space, you're not closed in but you go to any site and you're like in pens. You have no privacy. You're living in a caravan and 12 meters away there's another caravan and the windows are looking in and you've got to have the blinds closed all the time. That's not the way to live, you can't live like that. But that's what the government have chosen for us to do. We got to live like that.	Council sites, lack of choice and control over ones own destiny	Council Sites
13	Apart from that me boys now the last 6 7 months they can't get a job, there's nothing out there.	Difficulty getting work	
13	None of my sons except for **** can read and write and my daughters.	Literacy	
13	there's no future for the Traveller, the only way you will be able to travel in years to come is like this yard I've got and my brothers yard and go to my nephew's yard, that's the only way you'll be able to travel.	Erosion of GT culture	Eradication of GT ways
13	And Travellers have changed, completely changed. They're like the rest of the world, money is the god. Even my own..I keep telling them money isn't everything, you only need so much, a man can have it but he can't bring it to the grave with him.	Changing values base	Erosion of cultural heritage
14	we feel vulnerable all the time. Not sometime, all the time. What I mean is that nearly every day you go into a shop or the women go into a shop. The people around here now know we're Travellers and they'll get a security man to follow us around.	Feeling vulnerable, being watched , stigma of GT	Discrimination
14	My wife gets her shop from Tesco. In 4 years she knows everyone at the checkout and they all know her and yet every time her or one of my daughters goes in the security man is not 10 feet away from every	Not trusted.	Discrimination

Page	Issues	Categories	Themes - descriptions
	aisle that they go down.		
14	And it's the same when you go into a pub, if you go for a meal and that and maybe the kids are with you. And i don't care Travellers, country people or grogios whatever you call them their kids and that just run around and this and that and 9 times out of 10 they come over and say would you please get the kids off the premises or else you've got to leave the premises. You know it's things like that make you feel vulnerable because you can't turn around and start shouting the odds out and this and that. You just get up and leave. That's what I mean about being vulnerable.	Treated differently, stigma and labelling	Discrimination
15	Well that's the only situation we feel vulnerable when we're in a public place and people are following you around and asking you to leave. Things like that I've got high blood pressure as it is and when you go in a place like that and you walk into a pub, it goes quiet. You know well that these people know that you are a Traveller or someone knows you out of the community and wish we weren't Travellers. The pub will just go quiet and 4-5 minutes later they'll start chatting again and going back to normal. But you can see their eyes are on you the whole time. You face will get red with shame. Why should I be ashamed? I'm walking in and spending the same money as these people and yet get treated completely differently.	Treated differently, internalising the stigma, psychological vulnerability.	Ontological belonging
16	To me they were more focussing on little kids short dresses and to me I said what are they showing that for. Why are they showing the way the girl dances? You go into any nightclub and you'll see them all dancing similar. It was more or less putting the young girls down as badly behaved where it couldn't be further from the truth.	Media representations	Media

Appendix 12 Analysis of Phase 1 data



Appendix 13 Meaning Unit

Meaning Unit		
<p>1. Daisy - It was lovely on the road. But it's not too bad on here.</p> <p>2. Give them a choice; a better choice with the kids than being on the road. Or kids going to school and that.</p> <p><i>Vanessa</i> - Yeah. What made you decide to come here?</p> <p>3. Daisy - Well, I wouldn't have come here, my love. But when they made the sites, my husband, he used to work, but he took bad, and I come down on the site.</p> <p>4. He weren't here long then he died. About four year ago he died. I lost my husband down here.</p> <p>5. And if he hadn't been here, I wouldn't have come on the site.</p> <p><i>Vanessa</i> - Right. You would have carried on travelling...?</p> <p>6. Daisy - Yeah. Because it's a good life. Fresh air.</p> <p>7. The site is alright, but it would have been better if they'd have had them made out in the open. Out in the fields, you know what I mean?</p> <p>8. They've like...like they've got them now, there's a line there. There's built up round here. You can't see out nowhere. That's the only fault of the site. But if they made them out in the open it would be much better.</p>		

