The etemic model of Gypsy Roma Traveller community vulnerability: is it time to rethink our understanding of vulnerability?

Abstract

Aim: To present a new etemic model of vulnerability.

Background: Despite vulnerability being identified as a core consequence of health and health experiences there has been little research exploring the meaning of vulnerability as a concept. Yet being vulnerable is known to have dire physical/mental health consequences. It is therefore a fundamental issue for nurses to address. To date, the meaning of the term vulnerability has been influenced by the work of Spiers (2000, 2005). Spiers identified two aspects of vulnerability; the etic (external judgment of another persons' vulnerability and the emic (internal lived experience of vulnerability). This approach has led to a plethora of research which has explored the etic (external judgment) of vulnerability and rendered the internal lived (or emic) experience invisible. Consequences of this, for marginalised communities such as Gypsy Roma Travellers include a lack of culturally sensitive services compounding health inequalities.

Design: Position paper

Method: Drawing upon a qualitative phenomenological research study exploring the lived experience of vulnerability from a Gypsy Roma Travelling community (published previously), this paper presents a new model of vulnerability. This etemic model of vulnerability values both external and internal dimensions of vulnerability and argues for a fusion of these two opposing perspectives.

Conclusion and relevance to clinical practice: If nurses and other health and social care professionals wish to develop practice that is successful in engaging with Gypsy Roma Travellers then there is a need to both understand and respect their community. This can be achieved through an etemic approach to understanding their vulnerability achieved by eliciting lived experience alongside the appreciation of epidemiological studies. Doing so would enable the development and delivery of culturally sensitive services facilitating health access to this community. Only then, will their poor health status be successfully addressed.

Keywords: Vulnerable, Gypsy, Romany, Irish Traveller, indigenous, marginalised, patient voice, mental health, nursing, healthcare.

Summary Statement:

What does this paper contribute to the wider global clinical community?

- The concept of vulnerability, whilst a crucial aspect of nurses' professional practice
 has had little examination to date. This paper provides a critical examination of
 vulnerability providing a timely contribution to ongoing debates regarding
 vulnerability.
- The paper presents a new model of vulnerability; the etemic. This etemic approach
 provides a fusion of external, normative judgments of vulnerability alongside insights
 gained from understanding lived experiences of vulnerability. Arguing that both are
 crucial to develop services which are culturally sensitive and address health
 inequalities.
- This paper illustrates the etemic model of vulnerability with the exemplar of Gypsy Roma Travellers, drawing upon research exploring their lived experience of vulnerability. Thus providing an insight into this largely hidden community who experience significant health inequalities.

Introduction

Vulnerability is a dynamic and much contested concept that crosses the interface between the self and the social world. Nurses, amongst other human service professionals, are likely to encounter 'vulnerable people' throughout their professional career; because of this, statutory bodies of nursing and midwifery internationally recognise that managing and advocating for vulnerable people in society, is a key for professional practice (Americian Nursing Association 2010; Nursing Council of New Zealand 2012; Nursing and Midwifery Board of Australia 2006; Nursing Midwifery Council UK 2002). The International Council of Nurses (International Council of Nurses 2012) further asserts that nurses are ethically and morally bound to advocate for vulnerable populations within society.

Individuals can experience feelings of vulnerability, of being at risk of harm, danger, or in the throes of uncertainty, across a range of life events, including during periods of illness, through interactions with healthcare professionals, and entering unfamiliar surroundings such as hospitals, care or treatment facilities. Vulnerability within a healthcare setting, for example, can be linked to the loss of power and control over one's body during illness and is influenced by the power, prestige and position differentials between patient and medicine and healthcare practitioners (Parker et al. 2012; Heaslip 2015). There are long term health implications of vulnerability (Table 1), both physiological and psychological, arising from these experiences (Rogers 1997). It is, therefore, important that nurses have a depth of

understanding of some of the meanings of vulnerability and how, in their professional roles, can ameliorate prolonged experiences of vulnerability.

Numerous international studies on vulnerability have been conducted. This includes the exploration of 'vulnerable groups' such as: lower socio economic groups in the United States of America (USA) (Ahern et al. 2008), young Congolese in Uganda (Clark 2007), older people in Australia (Myall et al. 2009) and United Kingdom (UK) (Abley et al. 2011), asylum seekers in the UK (Stewart 2005), and children in both Turkey and the USA (Forsyth et al. 1996; Gleason and Evans 2004; Boles et al. 2005; Dogan et al. 2009). Vulnerability as a consequence of illness has also been explored: in cancer in Australia (Little et al. 2000), the Netherlands and the UK (Proot et al. 2003; Koffman et al. 2009), disability in Norway (Solveig Iversen et al. 2013), as well vulnerability experienced as a by-product of hospitalised care in Sweden (Sørlie et al. 2006). Despite these studies, vulnerability itself is still a poorly understood concept largely due to a lack of empirical studies exploring the phenomenon itself. Leroux et al. (2007) and Heaslip (2016), have addressed this shortfall, both utilising a descriptive phenomenological approach, Leroux in context of psychotherapy and Heaslip with Gypsy Roma Travellers.

The aim of this paper is to present a new model of vulnerability, the etemic approach, as an alternative to the traditional ways of perceiving the vulnerability concept as an etic fact identified by others. It however does not fully discount the etic in favour of an emic approach instead promotes a combination of the two. The etemic approach has been developed through research with Gypsy Roma Travellers (Heaslip 2015; Heaslip et al. 2016). This etemic approach contributes to a wider understanding of the phenomenon of vulnerability and can be used by nurses, health and social care practitioners to develop a better conception of it and, therefore, to improve their practices with vulnerable patients.

[Insert Table 1]

Background: What is already known regarding vulnerability?

Purdy (2004), in a concept analysis of vulnerability, identified its core attributes as that of susceptibility, chance and openness, all of which is argued to be central to understanding the academic explanations of vulnerability. At the heart of this according to Purdy, was being open in that being open an individual is therefore exposed and, therefore, receptive to experiencing vulnerability. In order to understand these somewhat opposite perspectives

consider for a moment, being a patient in a care facility. The patient, who is unwell, is often associated with having to expose themselves (openness) to another person (nurse or healthcare practitioner). Sharing personal health information with the healthcare team, who in turn assist in the patient's care, increasing the chances of improving the patient's health. However, during the course of this interaction there is also the possibility that the healthcare practitioner may reject or diminish the patient in some way, making them susceptible to being hurt or wounded. Linked to this is a lack of barrier, exposure or being without protection. Returning to the example of a patient in a care facility, the patient might have to present private parts of their body (physical exposure) or their health history (psychological exposure), in an environment where the patient will have little or no control. There are strange routines, sounds and terminology used all of which make the patient feel as though they lack control (they are without protection). In addition, the patient can be kept away from their family and loved ones exposing them to feeling isolated and alone (lack of barrier). The main antecedent (what happens before feeling vulnerable) was susceptibility, and in our care example, can include susceptibility to ill-health.

The consequences identified by Purdy (2004) were identified as disadvantage, harm, wounding or loss which can relate to the loss of the patient's once healthy self, as well as wider structural disadvantages of being ill such as financial loss, unemployment, or the physical harm or wounding that can occur following surgery. Whilst the concept review undertaken by Purdy identified that vulnerability was predominately perceived as negative, it has to be recognised that these attributes, antecedents and referents could be multi-dimensional, positive as well as negative (Purdy 2004). In order to understand this, take the possibility of falling in love. In this situation an individual takes a chance and opens themselves up to another human being, exposing themselves and sharing their innermost thoughts, beliefs and desires. In this situation they are also exposed, without protection and are susceptible to being rejected and hurt yet they also could find warmth, love and companionship. It is clear from both of the examples provided that vulnerability can be both positive and negative in a similar way to the concept of crisis (Parker 2007). However, within healthcare the predominant discourse is to view vulnerability negatively, which is something that nurses must strive to eradicate.

A range of models of vulnerability have been developed. Rogers' (1997) model of vulnerability described vulnerability as a dynamic interaction between the personal resources within the individual and the wider environmental supports, again suggesting links with crisis theory (Parker 2007). Alternatively, the model of vulnerability developed by Proot et al. (2003), in researching experiences of family members caring for a terminally ill person at

home in the Netherlands, presents a series of factors that increase or decrease the likelihood of feeling vulnerable (vulnerability increasing factors such as care burden, fear insecurity and/or vulnerability decreasing factors such as hope, keeping control and good support).

Spiers etic/emic perspective on vulnerability

It is the work by Spiers (2000) which has had the largest impact in understanding what vulnerability means from a health perspective. Spiers (2000:716) taking an anthropological perspective, identified two main approaches to viewing vulnerability; the "etic" and "emic" perspectives (figure 1).

[Insert Figure 1]

The etic perspective is one arising from the external evaluation or judgement of an outsider (for example nurse or health care practitioner) of the 'susceptibility to and possibility of harm' that may befall an individual. This reflects a normative perspective. This approach focuses upon groups of people and identifies their vulnerability on the basis of assumed objectivised criteria and from the outside. It is dichotomous, in that an individual is either vulnerable or they are not. It is this perspective which is often used in healthcare to denote community vulnerability. For example, Dr Chan, Director General of the World Health Organisation (2016), identified the following vulnerable groups; women, children, older people, indigenous people, migrants, rural workers, persons with disabilities and the poor. The majority of studies on vulnerability in healthcare have focussed upon this approach to vulnerability linked to biomedical outcomes regarding morbidity and mortality. However, this approach fails to give the nurse/health practitioner insight into how it actually feels, or what it feels, like to be vulnerable and creates simple binaries that reinforce normative expectations and behaviours in the provision of health and social care.

In contrast, Spiers (2000; 716) also identified an emic perspective of vulnerability 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. It is internally and subjectively evaluated or judged. In this perspective, vulnerability is exactly what the person experiencing it says it is, thus it is more holistic in nature, (see again crisis theory, Parker, 2007). The exploration of the emic perspective of vulnerability is relatively rare due to the difficulties encountered in

doing research with vulnerable groups that explores these insider perspectives (Rogers 1997) as well as the tacit privileging of normative ideologies of health care. Both Rogers (1997) and Spiers (2000) identified the need to seek and appreciate the lived experiences of those who had felt vulnerable in order to develop understanding of the emic perspective of the vulnerability phenomenon further.

Advantages and disadvantages of the etic approach

As already identified, the professional literature is dominated by the etic perspective, focussing on examining and identifying vulnerable populations or groups. Assigning the label of vulnerability as a mechanism to identify populations at risk of ill health; or identify individuals/populations in need of protection. This is influenced by societal values and a need for control and links with assumed taken-for-granted world views which do not focus on the power relations associated with such conceptions. There are, however, considerable benefits to perceiving vulnerability in this way to policy-makers and service planning. Firstly, it highlights populations with higher morbidity and mortality rates so that services can be tailored to address to prioritise these health care needs. Secondly, it is important that those at risk of abuse or manipulation are protected to ensure that they are not taken advantage or manipulated by others.

But the etic perspective has disadvantages also. Vulnerability is contextual; societal values often identify what is accepted or not and this itself can also create vulnerability. In order to understand this further let us consider the Gypsy Roma Travelling (GRT) community. It is important to note that whilst the term GRT is used in this paper they are not a homogenous community but comprise many different groups of Gypsies and Travellers each with distinct cultural identities (for further exploration see Heaslip et al. 2016). Historically, Gypsy Roma Travellers were largely nomadic, travelling from place to place working in agriculture on farms following the seasons. As such, seeing GRT on the road and pitching up on free land was common place and accepted in earlier times. However, today's Gypsy Roma Travellers are unable to travel and follow a nomadic life as nomadism in wider society is not the 'norm' nor culturally acceptable. As a result of this there are very few council-owned GRT sites that GRT can travel between (Van Cleemput 2007; Brown and Scullion 2009). This coupled with legislation making it illegal to pitch a wagon on the side of the road, has meant it is very difficult for GRT to find places to stay (Greenfields 2007). Therefore, they have been forced to pitch their wagons in inappropriate public spaces (such as car parks and play parks) that are not geared for human habitation. As a result they are constantly moved on by the police often only staying in areas for short periods of time. This makes it difficult to access on-going primary healthcare which perpetuates their vulnerable health status. There is a lack of waste disposal in these places which means that when the GRT are moved on, they leave behind them garbage waste which has to be removed at considerable cost to the local councils. In turn, this perpetuates the stigma and negativity towards this community increasing the discrimination that occurs (Turner 2002; Karner 2004; Convery and O'Brien 2012; Francis 2013) and perpetuates their vulnerability owing to a lack of belonging (Heaslip et al. 2016). However, these cultural understandings of vulnerability cannot be grasped using the etic view of vulnerability.

Seeing vulnerability in an etic way presents a reductionist perspective. Although it is important as a mechanism to identify unmet clinical need, it does little to explore neither why the vulnerability is there in the first place nor the reasons for health concerns within particular groups. For example, under the etic perspective of vulnerability, Gypsy Roma Travellers are defined as a vulnerable community as they experience poorer health in comparison to the settled community (Goward et al. 2006; Parry et al. 2007). However, knowing this alone does not necessarily enable services to be developed which address their vulnerable status. Without understanding how and why people experience vulnerability, practitioners and service managers cannot ensure that the services being developed truly meet a 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.

Advantages and disadvantages of the emic approach

As stated previously, it is the existential (lived) experience (emic perspective) that is the more silent in comparison to normative perspectives (etic perspective). Yet, the emic perspective offers a richer, broader and deeper definition and perspective of vulnerability from a humanistic perspective regarding the lives of individuals. It facilitates a deeper understanding of the experiences of individuals allowing nurses and healthcare practitioners, to see beyond homogenised groups and categories of people and move towards a focus on individuals and hearing their experiences. As Havel (1988;324) states:

"(t)he 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".

This notion of 'hearing the individual's voice' is gaining momentum politically within the UK (Scammell et al. 2015), reflecting the wider health and social care agenda of "nothing about me without me" (Department of Health 2010;13). This concept of 'hearing the patient's voice' is also growing internationally in recognition that service users can assist in developing and reviewing services to ensure they truly meet their needs (Happell et al. 2014). Despite the importance of engagement with Gypsy Roma Travellers being promoted in service development/enhancement (Department for Communities and Local Government 2012; p7), Adeagbo (2009) identifies that many barriers exist to achieving this including lack of time, confidence and skills as well as poor literacy levels in some individuals and groups using services.

Heaslip et al. (2016) explored this emic approach phenomenologically, considering the lived experiences of vulnerability from a Gypsy Roma Travelling community. This emic perspective identified a very different view of their vulnerability in comparison to the normative (etic) perspective which predominantly focuses upon the higher morbidity and mortality. Instead, the lived experience (emic) of feeling vulnerable focussed upon GRT individuals' internal and existential experiences, linked to their community values, beliefs and ways of being. Their vulnerability stemmed from their traditional ways of living being eroded by mainstream society. As such, they felt vulnerable because of a loss of heritage and cultural practices, feeling as a community that they were being eradicated. The GRT in the study felt pressurised to conform to living a way which was incongruent with their personal cultural values and this evoked their feelings of vulnerability (Heaslip 2015; Heaslip et al. 2016). This was reinforced as individuals and statutory services in mainstream society did not listen to them or their views; they felt powerless regarding the enforced change that was occurring to them. In order to fully appreciate this alternative perspective, let us understand Jimmy (fictitious name) an Irish Traveller's experience elicited through research (Heaslip 2015):

This day and age travellers, well you can't travel... well if you go on the side of the road you can have, well 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. So just saying, you get sick, so a lot of doctors, well a doctor will see you if you can get passed the receptionist. 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 ill. 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 when you're on the road it near impossible.

Talking about missing the ability to travel:

I miss the freedom.... Just like what today, I could think I'll go to, go down to Blackpool for a couple of months. You go down there and you never pull right in to the centre of Blackpool. You stay on the outskirts. Pull into a nice back road or a field. In the summer you get up in the morning on a nice sunny day and look around you and all you can see is beauty. Beauty is the land. You go outside and light a fire. You cook your meals on it. It's just so beautiful...Yet 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, they get you off in a couple of hours and you're gone.

On the loss of his community:

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.

Hearing Jimmy's perspective provides a real contrast to the vulnerability of GRT provided by etic, external normative judgements. In hearing the emic, there is a real sense of the tension, the vulnerability he experiences in not being able to live his life in congruence with his cultural beliefs and ways of being.

However, this approach also has it disadvantages. Seen alone, it could limit understanding of wider issues affecting vulnerability at a community/population level. Understanding and hearing Jimmy's perspective cannot predict the wider health implications of their prolonged experiences of vulnerability at a community level and therefore cannot assist commissioners of health services to determine what aspects of service provision needs to be developed. Large epidemiological studies, which are not individually focused of course, are required in

order to identify which particular aspects of poor health this community experience, so that services can be developed which have the greatest health benefit. In addition, emic explorations of vulnerability by their very nature would be smaller scale qualitative studies in order to ascertain the depth of understanding required and do not seek generalisability in a quantitative sense. Rather their aim is transferability relating to the extent to which the research findings can be transferred from one context to another or the degree to which the human dimension resonates with the reader. Yet in healthcare, a certain degree of generalisability is required in order to develop health services for a community at a national or international scale.

The way forward: the etemic perspective of vulnerability

We argue in this paper that nurses and healthcare practitioners need to move away from the traditional etic versus emic approach to viewing of vulnerability, dichotomised by Spiers (2000). We propose a third way, an etemic or fused perspective combining the advantages of both perspectives which privileges the voices of the individual alongside the professional discourse (see figure 2). To the left of the model are the normative external perspectives on vulnerability, on the right the internal lived experiences. However, these are perceived, not as separate components but a 'yin-yang', fusing both the reductionist and humanistic perspective in the new etemic approach. It is important see this model as a jigsaw, with each individual component from the left and the right representing a piece of the puzzle. Whilst focussing upon each puzzle piece is important in the building of an understanding, it is not until both pieces have been put together that you have a depth of understanding of the whole experience of what it means for a patient to be vulnerable.

[Insert Figure 2]

The etemic perspective in the care of the Gypsy Roma Traveller Population

In order to illustrate this further, we take the experience of mental health in Gypsy Roma Travellers. Taking aspects from the left of figure 2 (or the etic side), both Goward (2006) and Parry et al. (2007) identify that GRT experience poorer mental health than individuals within wider society. Yet questions have to be asked why? Using understanding gained from the right side of the model can help us to answer these questions. As identified Gypsy Roma Travellers are a cultural group experiencing huge cultural change (vulnerability of feeling pressured to conform to live a certain way) which they feel is imposed upon them by the settled community (Heaslip et al. 2016). They are unable to travel and be nomadic as they would wish owing to increased legislation which has criminalised nomadism. Instead they feel as though they have to live a life that is incongruent with their cultural values and who they are (Greenfields 2007). In addition to this, there is also a perception that they have no

voice and people are not willing to hear or understand their experience (vulnerability of powerlessness). Therefore they experience being 'done to' rather than worked alongside with. Such forced assimilation is viewed as a threat to their identity (vulnerability due to the loss of one's heritage). 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. All of this is damaging to one's sense of who one is and positive mental health. Therefore nurses and human service professionals working in mental health services need to bring together this understanding of poor mental health and the reasons why in an etemic approach. Having this depth of understanding is particularly important during times of crises or forced eviction (see Dale Farm Okely 2011), of which the mental health implications were never really highlighted or considered. Nurses in practice can also ensure that they work in an approach which actively promotes the listening to and valuing of the individual's voice and cultures of this community assisting in the development of trust and the building of a therapeutic relationship. Proactively there is a need to work with young people in this community building resilience and skills of coping with enforced change to avoid poorer mental health in future generations.

Likewise for nurses working in predominaltly physical health settings, GRT die on average 10-15 years younger (mechanism to identify populations at risk of ill health), yet we do not know why. Again this model could assist us in this understanding. We have already identified that this community are experiencing enforced cultural change (vulnerability due to loss of heritage, enforced cultural change, powerlessness, see figure 2) and this has an impact upon one's mental health. Yet Naylor et al. argues (2012) mental and physical health are interlinked and any mental health issues will negatively affect physical health. An example of this is smoking. Smoking rates in GRT communities are high (Parry et al. 2004), and this may be due to smoking being used as a mechanism to control nerves and anxieties which are also high in this community. This has an effect on physical health as this community who experience respiratory problems including asthma, bronchitis, and chest pain (Parry et al. 2004). Yet this is also a community that experience difficulty accessing services. Again the etemic model can assist here. In developing the understanding of the vulnerability experienced by the loss of one's cultural heritage, the health professional gains an insight into the lived world of this community and herein some of the challenges they face in accessing services. Some older GRT have difficulty with reading and writing, McCaffery (2009) estimates between 70-80% of adult are not able to write. This kind of etemic knowledge can enable the nurse or healthcare practitioner to have an insight into the difficulties GRT experience in accessing secondary care services such as hospital appointments which are communicated in a written format. This process makes services less accessible to a number of the community perpetuating their poor health status. This new understanding can help to explain why many GRT access healthcare through accident and emergency departments, often for treatment at later stages of their illness (Honer and Hoppie 2004). This lack of understanding in specialist services contributes to the higher morbidity and mortality levels of Gypsy Roma Travellers. This etemic knowledge can assist nurses and practitioners in developing community based open access healthcare drop in clinics for this community which could better address their healthcare needs as well as the importance of phoning individuals to remind them of their appointments at regular intervals.

Relevance for clinical practice

As has been presented here, the etemic perspective of vulnerability provides a unique and novel way of exploring both the lived experience of vulnerability alongside the more biomedical epidemiological approach. Focusing on the etemic can enable services to be developed that truly reduce health inequalities experienced by this group by enabling culturally cohesive services which accepts, empowers and values the Gypsy Roma Travelling community. For nurses working clinically, there are huge opportunities to gain insight into the lived world of individuals within this community during the assessment phase of the nursing process. However, in order for this to be achieved, the health assessment made by the professional must include holistic questions regarding the lives of the individual and not just a biomedical assessment focussing on the current physical or mental health complaint. Likewise healthcare providers should actively seek feedback from members in this community regarding their experiences of care in real time or family/friends initiatives (remembering that many older members in this community will not be able to read) as well as encouraging participation on service user/carers boards.

Using the etemic approach to vulnerability enables nurses to practice in a way which promotes the Human Rights based approach to healthcare advocated by the World Health Organisation (World Health Organisation 2015) (table 2).

[Insert Table 2]

Specifically understanding and valuing another's lived experience enables the professional to see beyond the label placed on the vulnerable population group and enables them to see a fellow human in a way that promotes non-discriminatory practice. Understanding the challenges experienced by communities, for example, with low literacy levels such as the

GRT, means that services can devise alternative means to written referrals, making these services more accessible and available to those who need them. Nursing that is focused upon understanding and building rapport with the community as part of the nursing assessment will enable the nurses to work in a more culturally sensitive way. Having more culturally sensitive services is also a means of being more accountable to the public purse. Currently, GRT access healthcare much later in an illness trajectory using secondary care services such as accident and emergency departments rather than preventative healthcare through primary care. This is less cost effective.

Limitations and future work

A potential critique of this model is its focus upon GRT as one particular community and small numbers, and therefore may not be transferable to other groups. This is a valid challenge. Vulnerability is a human phenomenon and as such we argue has to be studied contextually, within the human experience. Therefore, we propose that further work is required to explore the validity of this proposed model in other vulnerable groups to identify parts which resonate with them and their experience. One particular set of groups would be 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, like GRT, have higher poorer physical and mental health outcomes than the settled community, but also a separate cultural identify from the majority of the society in which they live. Therefore it indicates that further work is needed exploring the lived experiences of these communities to identify if the proposed model is also reflective their experiences.

Conclusion

This paper has presented a new model of vulnerability, arguing for a fusion between the reductionist bio-medical and an existential lived experience. This etemic model of vulnerability can be used by nurses and healthcare practitioners both in day to day provision of care of individual Gypsy Roma Travellers but also should be used in developing healthcare services to address the health inequalities. We argue it is only through the etemic approach which validates and recognises both the professional discourse as well as the individual voice (through appreciating the emic) that services be developed which are culturally sensitive and work with the community in addressing on-going health needs. The paper has presented an evolution in professional understanding of vulnerability arguing that an etemic perspective of understanding vulnerability is crucial not only in working with Gypsy Roma Travellers but working with other marginalised, hidden groups.

References

- Abley, C., Bond, J. and Robinson, L., 2011. Improving interprofessional practice for vulnerable older people: gaining a better understanding of vulnerability. *Journal of Interprofessional Care*, 25, 359-365.
- Adeagbo, A., 2009. *Involvement of Gypsy, Roma and Travelling Communities in Health and Social Care Policy and Practice*. London: National Voices.
- 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 (3), 691-703.
- Americian Nurses Association., 2010. The Nurse's role in ethics and Human Rights Position Satetment. Available from http://www.nursingworld.org/MainMenuCategories/EthicsStandards/Ethics-Position-Statements/-Nursess-Role-in-Ethics-and-Human-Rights.pdf. [Accessed 8.3.2016]
- Boles, R., Roberts, M. and Brown, K., Mayes, S.,, 2005. Children's Risk Taking Behaviors: The Role of Child-Based Perceptions of Vulnerability and Temperament. . *Journal of Pediatric Psychology*, 30 (7), 562-570.
- Brewer, M., 1996. When contact is not enough: Social identity and intergroup cooperation. *International Journal of Intercultural Relations.*, 20, 291-304.
- Brown, P. and Scullion, L., 2009. 'Doing research' with Gypsy-Travellers in England: reflections on experience and practice. *Community Development Journal.*, March 17, 1-17.
- Chan, M., 2016. A ruined planet cannot sustain human lives in good health [online]. http://www.who.int/gender-equity-rights/news/a-ruined-planet-cannot-sustain-lives/en/: World Health Organisation. Available from: 28.06].
- Clark, C., 2007. Understanding Vulnerability: From Categories to Experiences of Young Congolese People in Uganda. *Children & Society.*, 21, 284-296.
- Convery, I. and O'Brien, V., 2012. Gypsy-Traveller narratives: Making sense of place. *Narrative Inquiry*, 22 (2), 332-347.
- Delauney, T., 2013. Fractured Culture: Educare as a Healing Approach to Indigenous Trauma. *Th eInternational Journal of Science in Society*, 4, 53-62.
- Department for Communities and Local Government, 2012. Progress report by the ministerial working group on tackling inequalities experienced by Gypsies and Travellers.: Department for Communities and Local Government.
- Department of Health, 2010. Equity and Excellence: Liberating the NHS. Department of Health.
- Dogan, D., Ertem, I., Karaaslan, T. and Forsyth, B., 2009. Perception of Vulnerability Among Mothers of Health Infants in a Middle-Income Country. *Child: Care, Health and Development.* 35(6, 35 (6), 868-872.
- Forsyth, B., McCue Horwitz, S., Leventhal, J., Burger, J. and Leaf, P., 1996. The Child Vulnerability Scale: An Instrument to Measure Parental Perceptions of Child Vulnerability. *Journal of Pediatric Psychology.*, 21 (1), 89-101.
- Francis, G., 2013. Developing the cultural competence of health professionls working with Gypsy Travellers. *Journal of Psychological Issues in Organizational Culture*, 3 (S1), 64-77.
- Giddens, A., 1991. *Modernity and Self-Identity; Self and Society in the Late Modern Age.* Cambridge: Polity.
- Gleason, T. and Evans, M., 2004. Perceived Vulnerability: a comparision of parents and children. *Journal of Child Health Care*, 8 (4), 279-287.
- Goward, P., Repper, J., Appleton, L. and Hagan, T., 2006. Crossing Boundaries. Identifying and meeting the mental health needs of Gypsies and Travellers. *Journal of Mental Health.*, 15 (3), 315-327.
- Greenfields, M., 2007. Accommodation Needs of Gypsies/Travellers: New Approaches to Policy in England. *Social Policy & Society*, 7 (1), 73-89.

- Happell, B. B., L.McAllister, M.Lampshire, D. Roper, C., Gaskin, C. M., G.Wynaden, D.McKenna, B.Lakeman, R.Platania-Phung, C. and Hamer, H., 2014. Consumer involvement in the tertiary-level education of mental health professionals: a systematic review. *International Journal of Mental Health Nursing*, 23, 3-16.
- Havel, V., 1988. Letters to Olga. London: Faber and Faber Limited.
- Heaslip, V., 2015. Experiences of vulnerability from a Gypsy/Travelling perspective: A phenomenological study. (PhD). Bournemouth University.
- Heaslip, V., Hean, S. and Parker, J., 2016. Lived experience of vulnerability from a Gypsy Roma Traveller Perspective. *Journal of Clinical Nursing*, 25, 1987-1998.
- Honer, D. and Hoppie, P., 2004. The enigma of the Gypsy patient. RN, 67 (8), 33-36.
- International Council of Nurses, 2012. *The ICN Code of ethics for nurses.* International Council of Nurses.
- Johnson, M. and Webb, C., 1995. Rediscovering Unpopular Patients: the Concept of Social Judgement. *Journal of Advanced Nursing.*, 21, 466-475.
- Karner, C., 2004. Theorising power and resistance among travellers. *Social Semiotics*, 14 (3), 249-271.
- Khan, A. and Samadder, M., 2012. Weeping of the Forest: Unheard Voices of Garo Adivasi in Bangladesh. *International Journal on Minority and Group Rights*, 19, 317-326.
- Koffman, J., Morgan, M., Edmonds, P., Speck, P. and 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, 440-444.
- Leroux, P., Sperlinger, D. and Worrell, M., 2007. Experiencing Vulnerability in Psychotherapy. *Existential Analysis*, 18 (2), 315-328.
- Little, M., Paul, K., Jordens, C. and Sayers, E., 2000. Vulnerability in the narratives of patients and their carers: Studies of colorectal cancer. *Health*, 4 (4), 495-510.
- McCaffery, J., 2009. Gypsies and Travellers: literacy, discourse and communicative practices. *Compare*, 39 (5), 643-657.
- Myall, B., Hine, D., Marks, A., Thorsteinnsson, E., Brechman-Toussaint, M. and Samuels, C., 2009. Assessing Individual Differences in Perceived Vulnerability in Older Adults. *Personality and Individual Differences.*, 46, 8-13.
- Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M. and Galea, A., 2012. Long-term conditions and mental health: Cost of co-morbidities. London.
- Nursing Council of New Zealand., 2012. Code of Conduct for Nurses. Wellington: Nursing Council for New Zealand.
- Nursing and Midwifery Board of Australia., 2006., Code of Professional Conduct
- for Nurses in Australia. Melbourne: Nursing and Midwifery Board of Australia.
- Nursing Midwifery Council, 2002. *Practitioner Client relationships and the Prevention of Abuse*. London: Nursing Midwifery Council.
- Okely, J., 2011. The Dale Farm eviction. Anthropology Today, 27 (6), 24-27.
- Parker, J., 2007. Crisis intervention: a practice model for people who have dementia and their carers. *Practice*, 19 (2), 115-116.
- Parker, J., Ashencaen Crabtree, S., Chui, W., Humagai, T., Azman, A., Haselbacher, C., Ashkanani, H. and Szto, P., 2012. WAVE: working with adults who are vulnerable- a comparrision on curricula, policies and constructions. *Revista de Asistenţă Socială*, X1, 1-18.
- Parry, G., Van Cleemput, P., Paters, J., Walters, S., Thomas, K. and Cooper, C., 2007. Health Status of Gypsies and Travellers in England. *Journal of Epidemiol Community Health*, 61, 198-204.
- Parry, G., Van Cleemput, P., Peters, J., Moore, J., Walters, S., Thomas, K. and Cooper, C., 2004. *Health status of Gypsies and Travellers in England*. Sheffield: Sheffield University.
- Proot, I., Abu-Saad, H., Crebolder, H., Goldsteen, M., Luker, K. and 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.
- Purdy, I., 2004. Vulnerable: A concept analysis. Nursing Forum, 39 (4), 25-33.
- Rogers, A., 1997. Vulnerability, health and healthcare. *Journal of Advanced Nursing*, 26, 65-72.
- Scammell, J., Heaslip, V. and Crowley, E., 2015. Service user involvement in pre-registration general nurse education: A systematic review. *Journal of Clinical Nursing*, 25, 53-69.
- Shantz, J., 2010. 'The Foundation of our community': cultural restoration, reclaiming children and youth in an indigenous community. *Journal of Social Welfare & Family Law*, 32 (3), 229-236.
- Solveig Iversen, A., Graue, M. and Råheim, M., 2013. At the edge of vulnerability lived experience of parents of children with cerebral palsy going through surgery. *International Journal Qualitative Studies Health Well-being*, 8, 1-10.
- Spiers, J., 2000. New perspectives on vulnerability using emic and etic approaches. *Journal of Advanced Nursing*, 31 (3), 715-721.
- Spiers, J., 2005. A concept analysis of vulnerability. *In:* Cutliffe, J. and McKenna, H., eds. *The Essential Concepts of Nursing; building blocks for practice.* London: Elsevier.
- Stewart, E., 2005. Exploring the Vulnerability of Asylum Seekers in the UK. *Population, Space and Place.*, 11, 499-512.
- Stockwell, F., 1972. The Unpopular Patient. London: Royal College of Nursing.
- Swift, P., 2013. Changing ethnic identities among the Kuy in Cambodia: Assimilation, reassertion and the making of Indigenous identity. *Asia Pacific Viewpoint*, 54 (3), 296-308.
- Sørlie, 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., 15, 1240-1246.
- Turner, R., 2002. Gypsies and British Parliamentary Language; an analysis. *Romani Studies* 5, 12 (1), 1-34.
- Van Cleemput, P., 2007. Health Impact of Gypsy Sites Policy in the UK. Social Policy & Society, 7 (1), 103-117.
- World Health Organisation, 2015. *Health and Human Rights* [online]. http://www.who.int/mediacentre/factsheets/fs323/en/: World Health Organisation. Available from: 28.06].

Tables

Table 1 Health Implications of Vulnerability

Health implications of Vulnerability (Rogers 1997)

Physiological effects of vulnerability Psyc

Fatigue

Muscular tension Urinary frequency Weight loss Depression

Anorexia
Accident prone
Acne

Insomnia Back Pain

Gastro Intestinal distress Menstrual irregularities

Psychological effects of vulnerability

Helplessness Loss of control Lowered self esteem

Fear

Embarrassment
Loss of self-worth
Desperation
Powerlessness

Inability to express feelings

Anger Isolation Uncertainty Anxiety/worry

Inability to concentrate

Weakness

Table 2 Who Human Rights Based Approach to Health (2105)

- 1. Non-discrimination: The principle of non-discrimination seeks '...to guarantee that human rights are exercised without discrimination of any kind based on race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status such as disability, age, marital and family status, sexual orientation and gender identity, health status, place of residence, economic and social situation'1.
- 2. Availability: A sufficient quantity of functioning public health and health care facilities, goods and services, as well as programmes.
- 3. Accessibility: Health facilities, goods and services accessible to everyone. Accessibility has 4 overlapping dimensions:
 - o non-discrimination;
 - o physical accessibility;
 - economical accessibility (affordability);
 - information accessibility.
- 4. Acceptability: All health facilities, goods and services must be respectful of medical ethics and culturally appropriate as well as sensitive to gender and life-cycle requirements.
- 5. Quality: Health facilities, goods and services must be scientifically and medically appropriate and of good quality.
- 6. Accountability: States and other duty-bearers are answerable for the observance of human rights.
- 7. Universality: Human rights are universal and inalienable. All people everywhere in the world are entitled to them.

Figures

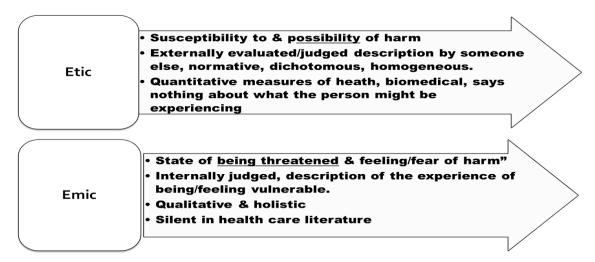


Figure 1 The Etic and Emic Approaches of Vulnerability adapted from Spiers (2000:716)

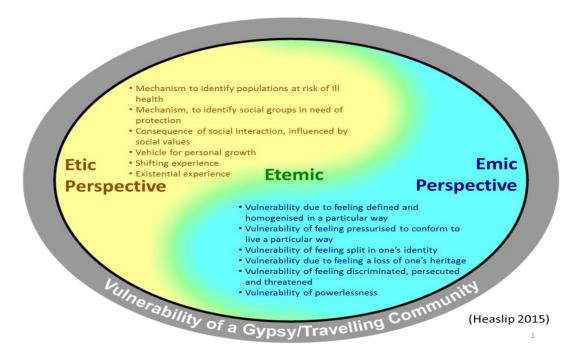


Figure 2 Etemic perspective of vulnerability