IMPROVING EQUITY AND CULTURAL RESPONSIVENESS WITH MARGINALIZED COMMUNITIES: UNDERSTANDING COMPETING WORLDVIEWS

WILSON, D., PhD, MA (Hons), RN

Professor Māori Health, Taupua Waiora Centre for Māori Health Research, Faculty of Health and Environmental Sciences, Auckland University of Technology, New Zealand

Corresponding author contact details:

Address: Private Box 92 006, Auckland 1142, New Zealand

Tel: +64 9 921 9999 ext 7293

Email: dlwilson@aut.ac.nz

HEASLIP, V., PhD, MA, BSc (Hons), Dip He, RN, DN

Principal Academic Department of Nursing and Clinical Science, Faculty of Health and Social Science, Bournemouth University, UK

JACKSON, D., PhD FACN

Professor of Nursing, Faculty of Health, University of Technology, Sydney, NSW, Australia 2007

IMPROVING EQUITY AND CULTURAL RESPONSIVENESS WITH MARGINALIZED COMMUNITIES: A POSITION PAPER

Abstract

Aim: The aim of this paper is to explore the impact of culture on health, healthcare provision and its contribution towards health inequity experienced by some marginalised communities.

Background: Health inequity is a global issue, which occurs across and within countries, and is the greatest barrier to worldwide health and the development of the human race. In response to this challenge, there is an international commitment to ensure universal health coverage based on the fundamental principle that individuals should be able to access healthcare services they need. Despite this, there is clear evidence that indigenous and other cultural minorities such as New Zealand Māori and Gypsy Roma Travellers still experience far poorer health outcomes when compared to the majority population. Furthermore, when they do access health care, their experiences are often not positive and this in turn results in reluctance to access preventative health care, instead accessing health services much later, reducing treatment options and compounding higher mortality rates. What is often not explored or examined is the impact of the different cultural beliefs of individuals in these communities and the nurses caring for them.

Design: This is a position paper drawing upon research experience with New Zealand Māori and Gypsy Roma Travellers. We critically review the experiences of health inequity of marginalised communities. It does so by examining how these communities may have a different world view to the nurses caring for them and it is this lack of understanding and valuing of alternative worldviews that contributes to the poorer health outcomes both communities face.

Conclusion and relevance to clinical practice: As nurses work with many different individuals and groups we have to find ways of ensuring a more embracing, culturally responsive health care environment which respects and values the beliefs of others.

Keywords: Cultural Issues, Competency, Indigenous Health, Health Promotion, Nurse-Patient Relationship, Patient-Centred Care, Discrimination, Ethnicity, Nursing Practice, Quality of Care

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

- This paper presents how health inequity is experienced by marginalised communities across the globe; as well as providing an in depth critical examination of two such communities (New Zealand Māori and Gypsy Roma Traveller).
- We discuss how world views of individuals in these two communities may be at odds with those of health care practitioners and how these differences can perpetuate health inequity.
- We highlight the potential role of nurses in addressing health inequity by facilitating access to health care; and argue that in order for this to occur nurses need to explore and acknowledge their own world views and those of their colleagues.

Introduction

The world, and the people that inhabit it are not homogenous, but hetergenous, consisting of a variety of different communities and groups, many of which have their own cultural values and practices. Yet this diversity can present difficulties and challenges, especially with regards to the provision of health care for such diverse population groups. A recent Lancet review on culture and health has identified a systematic neglect of the impact of culture on health and these authors argue this is currently the largest single barrier to the advancement of health across the world (Napier et al., 2014). While the disparities evident in health care and health outcomes can be attributed to a variety of things, some groups of people experience persistent, avoidable and unjust health inequities that in part can be attributed to the access to and quality of care they receive (Braveman, 2014; Marmot 2013). We will draw on two different marginalized communties to illustrate impacts of health care delivery on health for two groups who have ongoing inequities (McFadden et al., 2018; Ministry of Health, 2015): New Zealand Māori and Gypsy Roma Travellers with alternative worldviews of health and illness. They have worldviews that are at odds with the biomedical worldview that is prevalent in many Western healthcare services – that is, they have collective, holistic worldviews that are wellness and relationship focused, contrasting with the individual, illness or disease focus of biomedical approaches. While it can be argued that nurses practice from a holistic person-centred perspective, many nurses work within dominant healthcare institutions governed by biomedical approaches to healthcare. The aim of this paper is to explore the impact of culture upon health, healthcare provision and its contribution towards health inequity (Table 1), as well as the role that nurses can have in addressing this.

Background

Health outcomes identfied through morbidity and mortality rates vary across countries, typically high income countries have higher health status in comparision to low income countries. The World Health Organisation (WHO) (2011) identify a 23 year life expectency gap

between high and low income countries. This inequity of health status across the world has led to a greater focus and co-ordinated efforts at a global health level. In 2005, all WHO member states placed a commitment to achieve universal health coverage, based on the fundamental principle that individuals should have access to healthcare services they needed including 'prevention, promotion, treatment, rehabilitation and palliation without risk of financial ruin or impoverishment' (WHO, 2013). Achieving this was seen to be paramount for global health, a fundamental requisite for continued human development. Alongside this commitment for global health care access was the recognition that, even in wealthier nations, not all individuals have equal access to healthcare. The WHO (2017) constitution recently added advocating for healthcare equity. In this paper, we refer to health inequities rather than health inequalities because oftentimes the inequalities experienced by marginalized communities exist within contexts that are preventable and can be remedied. Moreover, the continued existence of these inequities is unjust, particularly for those who live with them on a daily basis (Braveman, 2014; Marmot, 2013).

<INSERT TABLE 1 HERE>

Not only are health inequities evident between countries, but even within countries there is a lack of parity regarding health status between different social groups across low, middle or high income countries. Typically, those with greater wealth and status have better health; in contrast, individuals with lower wealth and status experience poorer health outcomes (WHO, 2011). Interestingly, the structure of health care provision does not appear to have an impact in reducing health disparities within a country. For instance, the healthcare systems in the United States of America (US) mostly requires the purchase of services at the point of delivery through insurance. Such a system constrasts with a public health care system provided free (through taxation) on the basis of clinical need, such as the National Health Service in the United Kingdom (UK) and the New Zealand health care system. Despite the US spending more per capita on health care, it has reported to have greater inequities in the health of its people than other developed countries (Wilkinson, 2005).

Regardless of having developed healthcare systems, high income countries still experience drastic health inequities. In the US, the gap in life expectancy between the richest 1% and poorest 1% is 14.6 years for men and 10.1 years for women (Chettey et al. 2016), whilst in the UK, life expectancy is seven years lower in the poorest communties compared to the wealthiest whilst disability free life expectancy is 17 years lower (Buck & Maguire, 2015). In New Zealand, Māori (the Indigenous population) similar to other Indigenous people who have been colonized, suffer worse health and social inequities than other groups living in their respective countries (Delauney 2013). Forty percent of Māori live in the most deprived quintile

for New Zealand neighbourhoods (Ministry of Health, 2015). The life expectancy gap between Māori and others living in New Zealand is 7.2 years for women and 7.4 years for men (Statistics NZ, 2014). In the UK, the life expectancy gap between Gypsy Roma Travellers and the settled community is 11.9 years for women and 9.9 years for men (Barry et al. 1987). These systemic dfferences in health status of different population groups are identified as 'health inequalities' (WHO, 2011).

People's health results from a complex interplay between access to determinants of health, timely access to health services, and the quality of health care experiences (Marmot, 2013). In turn, determinants of health also influence people's quality of lifestyle and the resources they can access, which is for the most part beyond their immediate control (Isaac, 2015). Unequal access to health care services, such as a lack of access to necessary determinants of health or the unequal distribution of health care within societies are avoidable and contribute to health inequities. In fact, Marmot (2013) claims that health and health inequities are indicators of societal wellbeing, and are remediable.

Health inequities are common across marginalized communties who typically have little wealth or status within a society. As indicated, access to high quality healthcare can ameloriate these inequities (Marmot, 2013). Whilst the degree of impact of health care provision on health is hugely debated, Craig et al. (2006) argues that access to healthcare increases life expectancy and alleviates suffering. As such, marginalized communities require greater acess to health care support in order to address the health inequities they experience. Yet this demand is not necessarily matched with supply. Many individuals from marginalized communities find accessing health care services challenging. Reasons for this can be multi-faceted and include difficulty in accessing services due to physical ability (Heaslip et al. 2016a), structural barriers (O'Donnell, Tierney, O'Carroll, Nurse, & MacFarlane, 2016), poorer health literacy (Szczepura, 2005), language (O'Donnell et al., 2016), structural and interpersonal discriminatory practices (Jones, 2000), and poor cultural responsiveness (Heaslip et al. 2016b; Smith & Ruston, 2013; Kings Fund, 2006).

Internationally, health care providers have responded to health inequities by asserting both a committment towards reducing the health gap as well as addressing the barriers that perpetuate it. In the UK, NHS England set out six key equality objectives to be delivered in the NHS between 2016-2020 to promote access of people from marginalised communities to health services to generate improvement of their heath outcomes (NHS Engand, 2017). Likewise, New Zealand's Health Strategy (Ministry of Health, 2016) evisions a future whereby "**All** New Zealanders **live well, stay well, get well** [sic]" (p.13). This requires New Zealand

health services, and those working within them, for example nurses, knowing and being connected with the people – especially those experiencing inequities.

The enactment of health and relevant social policies, however, ultimately lies with health care practitioners working with patients on a day to day basis. Nurses are one such professional group, and are ideally placed to contribute to addressing health inequities by promoting timely health access and delivering high quality care, especially to those with high health needs. Nurses are the biggest professional group with the most day-to-day contact with the public across a variety of care contexts such as home, school, community and hospital environments. Not only are they the professional group with the greatest opportunity, but a comittment to vulnerable populations is at the ==heart of professional nursing==. Drake (1998) identifies that throughout history nurses have "ministered" to vulnerable populations, many of which were marginalised, and more recently Dawson, Nkowane and Whelan (2015) identified the role nurses have with vulnerable populations.

Health Services and Biomedical Worldviews

==A challenge for nurses is reconciling the different understandings that nurses, health services and those belonging to marginalized communities have about health, wellbeing and illness.== In this paper, worldviews are defined as ways of experiencing and thinking about the world we live in, evident in the commonly agreed beliefs and practices held by people belonging to particular groups. We contest that our worldview, whether personal or professional, influences and guides how we know, think and carry out our nursng practice. It is also one's worldview that influences our culturally-based points of reference, which are used to interpret and understand new and existing contexts and experiences such as health and health care experiences. Not only do the people using health services and those working within them bring with them their personal worldviews, but health services and health professional groups also have their own particular worldviews that inform how health services are structured and delivered. Although, in developed countries health services are for the most part based on biomedical constructs that drives their functioning.

The biomedical worldview is powerful and pervasive within healthcare systems globally in the developed world, focusing primarily on individuals and their illness and disease states. It is underpinned by mind-body duality, and scientific assumptions related to objectivity, measurement and reductionism. Therefore, a moral imperative from a biomedical perspective disease and illness (rather than health) is directed at problem-solving and treatment, intervention and curative activities (Tilburt & Geller, 2007). The WHO definition preceding the developments of cultural responsiveness in nursing practice, yet this definition remains relevant today. Regardless of the WHO's broader definition, a biomedical worldview of health

dominates the delivery of health care in developed countries. Despite the WHO in 1946 providing a broader and enduring definition of health (that is the "complete physical, mental and social well-being and not merely the absence of disease or infirmity"), a notable absence is the importance of the spiritual and family dimensions evident in Indigenous and other minority non-Western communities such as the Gypsy Roma Travellers living across Europe and the United Kingdom. However, Tilburt and Geller (2007) argue that without critiquing the worldview driving healthcare systems, practitioners like nurses are prone to engage in biased interactions with those patients who are marginalized and whose worldview is different, making it difficult to reconcile the differing worldviews.

Even though nursing ideology and rhetoric is based on concepts of caring, holism, and individualised or person-centred care, the majority of nurses in developed countries work and practice within biomedically structured healthcare services. This makes striving for these ideals fraught. Wilson and Neville (2008) highlighted this anomaly for those people who are considered vulnerable and marginalised, particularly when nurses adopt a problem-focused approach. Such approaches they maintain overlook people's understandings of health and illness and their life circumstances, and utilised a universal 'one-size-fits-all' approach to their practice.

Serving the needs of diverse communities involves being able to connect with and understand how those belonging to these communities see the world, particularly as it pertains to their health and wellbeing and ultimately their health care. The worldviews of those belonging to diverse communities are often at odds with the prevailing worldview driving health care providers' practice. As a result miscommunication, differences in understanding and responding to treatment and intervention in varying ways can emerge. Ideally, health practitioners should seek to understand patients' understanding of what health, wellbeing and illness means for them, the health care practices they already undertake, and their interpretations of treatments they are prescribed, it is not unusual for health professionals, including nurses, to hold patients responsible for not adhering to treatments or other interventions. Labelling patients as 'non-compliant, non concordant' (Russell et al. 2003) or a variety of other terms, all of which are based upon the premise that the patient is failing to follow the health care advice or treament presecribed by the healthcare provider. What is often not considered is that the health providers' plans of care may lack relevance and have little meaning because they cannot be reconciled with the patient's health beliefs, practices and their everyday realities. For instance, Māori women reported feeling devalued when their cultural beliefs or their life circumstances were not recognised or understood by health care providers (Wilson, 2008).

Worldviews of Marginalized Groups

In this section we present New Zealand Māori and Gypsy Roma Travellers who have alternative understandings of health and illness to those who subscribe to biomedical approaches. It is important to note that these groups are identified by broad collective terms, which include within them different and distinct groups who have nuanced variations in their views of the world. Therefore, assumptions cannot be made about individuals and the communities they live within. For example, within the New Zealand Māori community, there are numerous different communities that are iwi-based (tribally-based) or urban-based, and while they hold similar beliefs and values they all possess subtle differences in how they view the world and undertake their traditional cultural practices – for example, customs for engagement with visitors vary from area to area. For Gypsy Roma Travellers, this collective term includes different communities such as; Irish Travellers, Roma, Romani, Scottish Gypsies, Welsh Gypsies and Showmen. Whilst there may be some shared values regarding nomadism in these communities, there are also very distinct cultural differences and beliefs which will influence their behaviour and cultural practices. It is important therefore for nurses to remember is that despite groups like New Zealand Māori and Gypsy Roma Travellers having a generic labels that implies they are the same, diversity within their respective groups exists.

Traditionally, the New Zealand Māori concept of health was holistic in nature and referred to as hauora – which refers to a person's essence and vitality necessary to be well and healthy. Contrary to a biomedical view, hauora (holistic view of health) encompasses the multiple interconnected and interdependent dimensions related to people and their family – there are various models to represent Māori concepts of health such as Te Whare Tapa Whā (the four-sided house made up of whānau (extended family), wairua (spiritual), hinengaro (mind) and tinana (physical dimensions)), which is commonly used in New Zealand to explain the multidimensional nature of Māori views and understandings of health – that is, hauora. However, Te Wheke (the octopus) is another model used to represent the complexity of hauora, particularly the interdependence, and interconnection of the multiple dimensions that contribute to a person's and their family's wellbeing (Table 2). When one of these dimensions is out of balance, it impacts a person's hauora and total wellbeing. The focus of most New Zealand health services generally overlook important dimensions for a person, such as their wairua and whānau, because of the main focus on treating and responding to illness and disease. Indeed, prior to colonisation New Zealand Māori did not separate their health and wellbeing into these individual dimensions.

<INSERT TABLE 2 HERE>

Balance is crucial for Māori health and wellbeing, as is respecting and honouring people, places and objects that are tapu (sacred, restricted). In situations where someone has disregarded the restrictions placed on a person, place or object this breach may manifest itself in some form of sickness. Tapu was essentially a safety measure precolonisation (Durie, 1998). Correct cultural protocols or tikanga must be observed in order for tapu to be lifted and made noa (common) – for instance, some new mothers and their whānau may want the baby's placenta (whenua) so that they can return it to the land (also called whenua) they come from, using correct cultural processes.

Health services like hospitals are seen as foreign environments, which make many Māori, whether they subscribe to traditional beliefs or not, feel uncomfortable. Often their beliefs and important cultural practices are ignored such as karakia (recital of a chant or prayer) to spiritually soothe the way for what is to happen. Furthermore, many Māori also engage in traditional healing practices such as rongoā (Māori traditional healing practices). The tendency for most health care providers to ignore the importance of their wairua (spiritual dimension) and their whānau can increase their discomfort (Wilson, 2008; Wilson & Barton, 2012). The disregard of Māori beliefs, values and practices coupled with discriminatory practices of health professionals means it is not unusual for New Zealand Māori to avoid health services. However, inequities affecting New Zealand Māori mean they are more likely to die prematurely, be hospitalised or die from illnesses that are amenable to prevention with effective primary health care (Ministry of Health, 2015). They are also more likely to experience adverse events when they do engage with health services (Rumball-Smith, Sarfati, Hider & Blakely, 2013).

Perceptions of health and illness can also differ within Gypsy Roma Traveller communities. A study of Roma in Lasi and Cluj (Dumitras et al., 2013) identified that disease can be viewed 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; however there was a degree of fatalism with regard to health and illness irrespective of current health behaviour. This is linked to a strong religious/spiritual belief that influences health behaviour, especially accessing preventative health services. For example, premature morbidity may not necessarily be linked with smoking habits when people hold fatalistic beliefs. Poorer physical health is accepted, and to some degree expected, within Gypsy Roma Traveller communities especially with aging (Van Cleemput et al. 2007); as such, the focus of health is more upon quality of life rather than quantity of years.

Gypsy Roma Traveller communities tend not to access medical advice, preferring to seek advice from others within their own community (Dumitras et al. 2013, Dion 2008) or to utilise herbal or traditional treatments passed down through the generations. Reasons for this are twofold; firstly due to cultural beliefs regarding medicine and healthcare and secondly due to the discriminatory experiences and years of persecution by wider society. Okely (1983) identifies that Gypsy Roma Travellers, when unwell, prefer to remain at home whenever possible because hospitals are considered concentrations of gorgia/gaujo (non gypsy) disease. In addition, she argues that Gypsies believe that the gorgia are condemned as *'mochadi'* (meaning polluted) because they fail to distinguish between the inner and outer body (Okely, 1983). Okely therefore, concludes that Gypsy Roma Travellers will seek admission to hospital when they believe they are 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 Roma Travellers to be nursed in a hospital setting. They may seek to discharge themselves or simply leave against medical advice; often when still very sick. Gypsy Roma Travellers may also find eating in hospital problematic because of concerns regarding the preparation and cleanliness of the environment, and may prefer instead to have food and cutlery brought from home.

Other challenges that face Gypsy Roma Travellers women in health care are cultural gender distinctions that occur within the community. In research with Gypsy Roma Travellers it has become apparent that women do not discuss personal bodily functions with the men in their communities, instead these areas as designated 'women's issues' and tend to be discussed with other women in the community. This makes it very hard when accessing health care as many Gypsy Roma Travellers women and their husbands would be uncomfortable if a male practitioner treated a female, especially if the health problem was gynaecological or gastric in nature. Discussing bowels, bowel movements or menstruation will be very difficult as they are considered very private (McFadden et al., 2018; Heaslip 2015).

Like New Zealand Maori, Gypsy Roma Travellers tend not to access preventative health care, instead entering healthcare services much further down the illness trajectory. Yet when they do access health care, they are often faced with cultural barriers (Heaslip et al. 2016b), which result in fracturing the already fragile bond of trust between the practitioner and the community, as well as discrimination (Cemlyn et al. 2009, Smith & Ruston 2013), all of which contributes to the healthcare inequity they experience.

Challenges of being culturally responsive

Achieving equity in health care requires nurses, along with other health professsionals, to examine various aspects of their personal and professional practice. Culturally responsive

practice involves nurses not only being culturally competent, inclusive, respectful and attending to people's cultural needs during their health care experiences, but also that patients and their families feel culturally safe (Wilson & Hickey, 2015). Fundamental to being culturally responsive is establishing meaningful and genuine relationships with people, and involving them in the decision making regarding their care (Browne et al., 2016). Culturally responsive care could be considered fundamental to person-centred care, which is predicated on respectful interactions and collaborative practice (Olsson, Forsberg, & Bjersá, 2016). Yet, there are a number of challenges and factors that can impact delivering culturally responsive nursing care.

From an equity perspective, approaching care from a 'one-size-fits-all' stance is fundamentally flawed and culturally dangerous. Universal practice approaches, based on the concepts of equality, are be evident in statements like "I treat all my patients the same," "Everyone is equal," or "Everyonne has equal opportunities". Ignoring people's cultural beliefs and ways of life by imposing a health system's cultural practices onto everyone or by not acknowledging people's cultural differences become barriers to culturally responsive nursing practice. Similarly, judging others against the dominant cultural beliefs and practices, whether they are personal or professional, does little to respect other's cultural differences. Furthermore, practise that is equity informed requires different approaches being taken to achieve the same or equal outcomes.

Chambers and Narayanasamy (2008) found variability in nurses' practice and undertaking prescribed professional roles and expectations, and instead nurses are likely to use personal health values and attitudes to inform their professional nursing practice. Social and professional nursing roles, and the associated expectations and obligations may in fact conflict with a nurse's personal health values and beliefs nurses. In such situations where cognitive dissonance occurs, personal ingrained values and beliefs are drawn on to inform professional practice and decisions. Chambers and Narayanasamy maintain if left unexamined, personal values and beliefs can unduly influence and impact on the effectiveness of their nursing practice.

Caring is an important component of nurses' practice, and undoubtedly nurses approach their daily work with patients in well-intentioned ways with the aim to help them to improve their health and wellbeing. Even though nurses have these best intentions and they belong to a profession based on ideologies of caring and person-centred practice, people from marginalized communities (such as New Zealand Māori and Gypsy Roma Travellers) report discomfort when engaging with health service providers including nurses (Francis 2013). A loss of power, control and status when engaging with health care services is compounded by

being silenced, and can increase patients' and families vulnerability (Heaslip et al. 2016a). People belonging to marginalised groups have also reported discrimination and observe they are often treated differently than other people receiving similar health care services (Wilson & Barton, 2012). Moreover, nurses are not always seen to be caring (Papastavrou et al., 2012). Discrimination and unconscious biases are recognised as determinants of health causing physiological and psychological stress that is associated with negative health consequences (Harris et al., 2012; Ramaswamy & Kelly, 2015). However, caring is complex especially when working with others who hold differing worldviews.

The role of culture in health care has long been attended to in the nursing literature, yet approaches to nurses' practice often ignore individual's cultural norms and ways of doing things. Instead, at an individual level, nurses can adopt approaches that draw on unvalidated assumptions, stereotypes and prejudices especially regarding those people who belong to marginalized communities (Francis 2013). Such approaches neglect the complexity of individuals and their lives, and can perpetuate inaccuracies in nursing diagnoses and decision making, instead promoting care that lacks cultural competence. However, Engebretson, Mahoney and Carlson (2008) claim cultural competence is an abstract concept that makes it difficult for nurses to be culturally inclusive in their practice. This is because the group culture within which nurses practice provide challenges, and at an organisational level, policies and service delivery plans make culturally inclusive practice difficult for nurses to undertake. Cultural competence, at its best, could be considered patient or family-centred care because culture is integral to patients' and families experiences and expectations of health care and ultimately their appraisal of its quality (Engebretson et al. 2008).

Given that most nurses do not start their work day thinking that they would treat some patients differently to others, unconscious biases could explain why patients belonging to marginalized communities report that they are treated differently or that their health need is unmet. Unconscious or implicit biases are contributors to poor quality health care and ineffective communication. Haider et al. (2015) investigated the role nurses play in perpetuating or reducing health care disparities. They found that registered nurses had implicit class and social class biases despite denying having personal racial or social status preferences, although these biases were not significantly associated with their clinical decision making. Nonetheless, Haider et al. (2015) found that these implicit biases did influence their treatment choices that lead to unequal treatment. Furthermore, those working in health services may invariably not recognise the experiences and realities of those belonging to marginalized communities such as colonisation, racism and discrimination (Browne et al., 2016). Being aware of those factors that influence the way nurses may or may not practice is essential if they are to deliver high quality health care and contribute to reduced health inequities.

Becoming aware of the challenges and barriers and then critically reflecting on these is key for the delivery of care that is equity oriented and culturally responsive. Thus, engaging in critical reflexivity is one strategy that nurses can undertake to explore their personal values, beliefs and attitudes and how these affect carrying out their nursing practice. Timmins (2006) defines critical reflexivity as a "...personal analysis that involves challenging personal beliefs and assumptions to improve professional and personal practice" (p. 49). Critical reflexivity is an ongoing practice that involves analysis and questioning of practice actions and decisions, along with the beliefs and assumptions inherent in the cultures of nurses, institutions and patients and their families, and how their inform and influence the nurse's practice. The aim is to improve competence and appropriate nursing care decisions that uses not only practice knowledge and research evidence, but also includes patients and family as key informants about their health, life and experiences. Undertaking critical reflexivity requires nurses to adopt an attitude of humility in order to respect patients and families as equals, and collaboratively engage with them so that their health needs can be met better (Timmins, 2006).

Person-centred holistic care

Much is written about person-centred care, but for marginalized communities this seems to get lost amidst an exclusive focus on individuals and universal approaches. Despite expectations that nurses provide person-centred care, guidance to operationalize this in their everyday practice is absent (Feo et al., 2017; Ross, Tod, & Clarke, 2015). Furthermore, Entwistle and Watt (2013) claim that while much is talked about person-centred care its value remains implied rather than explicit and they question whether it is unrealistic in practice. The efficacy of person-centred care and its implementation remains unmeasured (Savundranayagam, 2012).

Person-centred care that considers the holistic beliefs of people is important for establishing the trust of those belonging to marginalized communities and the delivery of quality and equitable care (Doherty & Thompson, 2014; Ross et al., 2015). KAI (knowledge-action-integration) is a culturally responsive framework that can be used for person-centred holistic care, Knowledge requires nurses to consider their personal and professional cultural beliefs and values, and know about people's socio-cultural backgrounds; action refers to how they interact with patients and their families; and integration is the inclusion of important cultural practices and needs into their plans of care (Wilson & Hickey, 2015). This includes recognising that what is important to patients may extend beyond their physical presence and their presenting illness or disease. For example, for many Māori patients their wairua (spiritual wellbeing) and whānau (extended family) are very important to their health and wellbeing. Person-centred holistic care involves the development of inclusive working relationships with

patients and their family, and in the process incorporates the multiple dimensions and influences that affect the quality of their health care – particularly recognising the important role of their spiritual wellbeing and the role of their family in this. The inclusion of families is particularly important when patients are unable to be involved in decision making and their health care for health or cultural reasons.

In contrast with the nuclear family philosophy dominant in the pejorative community, both the New Zealand Māori and Gypsy Roma Travellers communities tend to have a strong extended family culture which can include siblings, parents, grandparents as well as cousins and second cousins. Furthermore, both New Zealand Māori and Gypsy Roma Travellers communities place significant importance on family (Jesper, Griffiths, & Smith, 2008), being close to and staying with one's family unit. This often results in Māori and many Gypsy Roma Travellers living close to or alongside these extended family units (Wetzel, Dean, & Rogers, 1983). This focus on family contrasts with health care services attending to the needs of individuals, and is frequently a source of tension between a service's focus on individuals and the collective focus of these families. A collective orientation, as seen with New Zealand Māori and Gypsy Roma Travellers, means that individual members have responsibilities and obligations to other family members and to the collective as a whole.

This close family unit is extremely important for the health and wellbeing of the entire family when a member of the community becomes ill. When a family member is unwell then other family members have an integral obligation to be present to support and care for not only the unwell person, but also the whole family (Wilson & Barton, 2012; Wilson & Hickey, 2015). Hospitals also often fail to appreciate the family culture of Gypsy Roma Travellers and New Zealand Māori especially with regard to visiting hours and visitor numbers. It is normal practice for large family groups to gather when a family member is dying or admitted to hospital (Durie, 1998; Wetzel et al., 1983). Therefore, numbers of visitors can vary between 40 family members for average ailments up to 100 for serious health issues of senior Gypsy Roma Travellers family members (Vivian & 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. For Gypsy Roma Travellers, in this aspect of their lives, there is a strong matriarchial presence, accessing advice and support from the eldest female member of the family is important. Similarly, for New Zealand Māori the presence of family is cruical to fulfill their nurturing and support obligations and for their wairua (spiritual wellbeing).

Nurses can begin by establishing a relationship with both patient and their family from marginalized communities to build trust. In order to do this, they should display attitudes that are genuine, empathetic, and compassionate, actively assist patients and family participation

in decision making about their health care, and where necessary act as their advocate for their cultural needs. Connecting with family members is just as important as connecting with an unwell individual. Such an approach is fundamentally based on establishing trust, which involves:

- giving the patient and family their full attention;
- establishing their needs, concerns and values;
- being willing to know and understand the patient and family so that the nurses actions are both acceptable and appropriate; and
- undertaking ongoing evaluation of the relationship quality and functioning (Doherty & Thompson, 2014; Feo et al., 2017; Ross, Tod, & Clarke, 2015).

Doherty and Thompson (2014) stress this can only be achieved when patients and their families are engaged and willing to be involved – for marginalized communities who often are suscipious of health professionals, this involves securing their trust.

Implications for Practice

It is clearly evident that nurses have a key role in promoting health care engagement with individuals from marginalised communities who experience heath inequity. However, in order for this to occur there needs to be some critical reflection regarding the degree to which the healthcare provison is culturally embracing of others world views. We contend that this reflection needs to occur at three levels (individual, group and organisational). At the individual level, the nurse needs to be open to explore their own personal views, beliefs and criticaly examine the degree to which these influence their professional practice. At a group level, there needs to be an examination of the cuture of the environment exploring how people with differing worlds views are perceived and spoken about and whether this perpetuates a negative connotation of that client group. Lastly, at a organisational level nurses need to expore ways of ensure that diverse beliefs, values and perspectives of these communities are collated and presented when new services are developed or re defined to ensure that practice approaches are able to embrace people from to these communities. Undertaking this would work towards addressing the health inequity experienced by these communities in the access of health care services and the quality of care received.

Glossary

Hauora	Holistic worldview that is spiritual and environmentally connected
Hinengaro	The mind – cognitive and emotional aspects of a person
Noa	A state free from restrictions

Rongoā	Māori traditional healing practices
Tapu	Being in a state that is sacred or restricted
Te Wheke	The octopus
Tinana	Physical dimension of a person
Wairua	Spiritual dimension of a person
Whānau	Extended and collective family network
Whenua	Refers to both the land or the placenta
Te Whare Tapa Wha	Four-sided house

References

Barry J, Herity B, Solan J. (1987). The Travellers' health status study, vital statistics of travelling people, 1987. Dublin, Ireland: Health Research Board.

Braveman, P. (2014). What are health disparities and health equity? We need to be clear. *Public Health Reports, 129*(Suppl 2), 5-8.

Browne, A. J., Varcoe, C., Lavoie, J., Smye, V., Wong, S. T., Krause, M., Fridkin, A. (2016). Enhancing health care equity with Indigenous populations: Evidence-based strategies from an ethnographic study. *BMC Health Services Research, 16*, 544. doi:10.1186/s12913-016-1707-9

Buck, D., & Maguire, D. (2015). *Inequalities in life expectancy; Changes over time and implications for policy.* London, UK: Kings Fund.

Cemlyn, S., Greenfields, M., Burnett, S., Matthews, Z., & Whitwell, C., (2009). *Inequalities Experienced by Gypsy and Traveller communities: A Review.* Manchester, UK: Equality and Human Rights Commission.

Chambers, D., & Narayanasamy, A. (2008). A discourse and Foucauldian analysis of nurses' health beliefs: Implications for nurse education. *Nurse Education Today, 28*(2), 155-162. doi:10.1016/j.nedt.2007.03.009

Craig, N., Wright, B., Hanlon, P., Galbraith, S., (2006). Does health care improve health? *Journal of Health Services Research & Policy, 11*(1), 1-2. doi:10.1258/135581906775094299

Dawson, A. J., Nkowane, A. M., & Whelan, A. (2015). Approaches to improving the contribution of the nursing and midwifery workforce to increasing universal access to primary health care for vulnerable populations: A systematic review. *Human Resources for Health, 13*, 1-23. doi:10.1186/s12960-015-0096-1

Dion, X., 2008. Gypsies and Travellers: Cultural influences on health. *Community Practitioner, 81*(6), 31-34.

Doherty, M., & Thompson, H. (2014). Enhancing person-centred care through the development of a therapeutic relationship. *British Journal of Community Nursing, 19*(10), 502-507. doi:10.12968/bjcn.2014.19.10.502

Drake, V., 1998. Process, perils and pitfalls of research in prison. *Issues in Mental Health Nursing, 19*, 41-52. doi:10.1080/06128498249204

Dumitras, S., Gramma, R., Roman, G., Parvu, A., Enache, M., Moisa, S., & Loan, B. (2013). Considerations on the particularities of the illness and death perception for Roma people. Revists *Románă De Pediatrie, LXII* (1), 69-73.

Durie, M. (1998). *Whaiora: Maori health development* (2nd ed.). Auckland, New Zealand: Oxford University Press.

Engebretson, J., Mahoney, J., & Carlson, E. D. (2008). Cultural competence in the era of evidence-based practice. *Journal of Professional Nursing, 24*(3), 172-178. doi:10.1016/j.profnurs.2007.10.012

Entwistle, V. A., & Watt, I. S. (2013). Treating patients as persons: A capabilities approach to support delivery of person-centered care. *American Journal of Bioethics, 13*(8), 29-39. doi:10.1080/15265161.2013.802060

Feo, R., Conroy, T., Marshall, R. J., Rasmussen, P., Wiechula, R., & Kitson, A. L. (2017). Using holistic interpretive synthesis to create practice-relevant guidance for person-centred fundamental care delivered by nurses. *Nursing Inquiry, 24*(2). doi:10.1111/nin.12152

Francis, G., 2013. Developing the cultural competence of health professionals working with Gypsy Travellers. *Journal of Psychological Issues in Organizational Culture*, 3 (S1), 64-77. doi:10.1002/jpoc.21074

Haider, A. H., Schneider, E. B., Sriram, N., Scott, V. K., Swoboda, S. M., Zogg, C. K., . . . Cooper, L. A. (2015). Unconscious race and class biases among registered nurses: Vignette-based study using implicit association testing. *Journal of the American College of Surgeons, 220*(6), 1077-1086. e1073. doi:10.1016/j.jamcollsurg.2015.01.065

Harris, R., Cormack, D., Tobias, M., Yeh, L.-C., Talamaivao, N., Minster, J., & Timutimu, R. (2012). The pervasive effects of racism: Experiences of racial discrimination in New Zealand over time and associations with multiple health domains. *Social Science & Medicine, 74*(3), 408-415. doi:10.1016/j.socscimed.2011.11.004

Heaslip, V., (2015) Experiences of Vulnerability from a Gypsy/Travelling Perspective: A Phenomenological Study. (PhD), Bournemouth University, Bournemouth.

Heaslip, V., Hean, S., & Parker, J., (2016a). Lived experience of vulnerability from a Gypsy Roma Traveller perspective. *Journal of Clinical Nursing, 25*, 1987–1998. doi:10.1111/jocn.13223

Heaslip, V., Hean, S., & Parker, J. (2016b). The etemic model of Gypsy Roma Traveller community vulnerability: Is it time to rethink our understanding of vulnerability? *Journal of Clinical Nursing.* doi:10.1111/jocn.13499

Jesper, E., Griffiths, F. & Smith, L. (2008). A qualitative study of the health experience of Gypsy Travellers in the UK with a focus on terminal illness. *Primary Health Care Research & Development, 9*, 157-165. doi:101017/S1463423608000613

Jones, C. P. (2000). Levels of racism: A theoretic framework and a gardener's tale. *American Journal of Public Health, 90*, 1212-1215. doi:10.2105/AJPH.90.8.1212

Kinds Fund. (2006). *Access to health care and minority groups.* London, UK: Kings Fund.

McFadden, A., Siebelt, L., Gavine, A., Atkin, K., Bell, K., Innes, N., . . . MacGillivray, S. (2018). Gypsy, Roma and Traveller access to and engagement with health services: A systematic review. *Eur J Public Health, 28*(1), 74-81. doi:10.1093/eurpub/ckx226

Marmot, M. (2013). *Health gap: The challenge of an unequal world.* London, UK: Bloomsbury.

Ministry of Health. (2015). *Tatau Kahukura Māori health chart book 2015* (3rd ed.). Retrieved from http://www.health.govt.nz/publication/tatau-kahukura-maori-health-chart-book-2015-3rd-edition

Minister of Health. (2016). *New Zealand Health Strategy: Future direction.* Retrieved from http://www.health.govt.nz/system/files/documents/publications/new-zealand-health-strategy-futuredirection-2016-apr16.pdf

Napier, D., Ancarno, C., Butler, B., Calabrese, J., Chater, A., Chatterjee, H., … Wool, K., (2014). Culture and health. *The Lancet, 384*; 1607-1639. doi:10.1016/S0140-6736(14)61603-2

NHS England. (2017). *NHS England response to the specific equality duties of the Equality Act 2010: NHS England's equality objectives and equality information*. Available from: https://www.england.nhs.uk/wp-content/uploads/2012/04/NHS-England-SED-Response.pdf

O'Donnell, P., Tierney, E., O'Carroll, A., Nurse, D. & MacFarlane, A. (2016). Exploring levers and barriers to accessing primary care for marginalized groups and identifying their priorities for primary care provision: A participatory learning and action research study. *International Journal for Equity in Health.* 15, 197.doi:10.1186/s12939-016-0487-5

Okely, J. (1983). *The Traveller-Gypsies.* Cambridge, UK: Cambridge University Press.

Olsson, C., Forsberg, A., & Bjerså, K. (2016). Safety climate and readiness for implementation of evidence and person centered practice - A national study of registered nurses in general surgical care at Swedish university hospitals. *BMC Nursing, 15*, 1-12. doi:10.1186/s12912-016-0174-2

Papastavrou, E., Efstathiou, G., Tsangari, H., Suhonen, R., Leino-Kilpi, H., Patiraki, E., Merkouris, A. (2012). A cross-cultural study of the concept of caring through behaviours: patients' and nurses' perspectives in six different EU countries. *Journal of Advanced Nursing, 68*(5), 1026-1037. doi:10.1111/j.1365-2648.2011.05807.x

Ramaswamy, M., & Kelly, P. J. (2015). Institutional racism as a critical social determinant of health. *Public Health Nursing, 32*(4), 285-286. doi:10.1111/phn.12212

Ross, H., Tod, A. M., & Clarke, A. (2015). Understanding and achieving person-centred care: The nurse perspective. *Journal of Clinical Nursing, 24*(9/10), 1223-1233. doi:10.1111/jocn.12662

Rumball-Smith, J., Sarfati, D., Hider, P., & Blakely, T. (2013). Ethnic disparities in the quality of hospital care in New Zealand, as measured by 30-day rate of unplanned readmission/death. *International Journal of Quality in Health Care, 25*(3), 248-254. doi:10.1093/intqhc/mzt012

Russell, S., Daly, J., Hughes, E. & OP'T Hoog, C., (2003). Nurses and 'difficult' patients: negotiating non-compliance. *Journal of Advanced Nursing*, 43(3), 281–287. doi: 10.1046/j.1365-2648.2003.02711.x

Savundranayagam, M. Y. (2012). Person-centered care: Measurement, implementation, and outcomes. *Clinical Gerontologist, 35*(5), 357-359. doi:10.1080/07317115.2012.702646

Smith, D., & Ruston, A. (2013). 'If you feel that nobody wants you you'll withdraw into your own': Gypsies/Travellers, networks and healthcare utilisation. *Sociology of Health & Illness, 35*(8), 1196–1210. doi:10.1111/1467-9566.12029

Szczepura, A. (2005). Access to health care for ethnic minority populations. *Postgraduate Medical Journal,* 141–147. doi:10.1136/pgmj.2004.026237

Statistics New Zealand. (2014). Quick stats: About culture and identity. Retrieved from http://www.stats.govt.nz/Census/2013-census/profile-and-summary-reports/quickstats-culture-identity.aspx

Tilburt, J., & Geller, G. (2007). Viewpoint: The importance of worldviews for medical education. *Academic Medicine, 82*(8), 819-822. doi:10.1097/ACM.0b013e3180d098cc

Timmins, F. (2006). Critical practice in nursing care: Analysis, action and reflexivity. *Nursing Standard, 20*(39), 49-54. doi:10.7748/ns2006.06.20.39.49.c4172

Van Cleemput, P., Parry, G., Thomas, K., Peters, J. and Cooper, C. (2007). Health-related beliefs and Experiences of Gypsies and Travellers: A qualitative study. *Journal of Epidemiology and Community Health*, 61, 205–2. doi:10.1136/jech.2006.046078

Vivian, C. & Dundes, L. (2004). The crossroads of culture and health among Roma (Gypsies). *Journal of Nursing Scholarship, 36*(1), 86-91. doi:10.1111/j.1547-5069.2004.04018.x

Wetzel, R., Dean, M., & Rogers, M. (1983). Gypsies and acute medical intervention. *Pediatrics, 72*(5), 731-735.

Wilkinson, R. G. (2005). *The impact of inequality: How to make sick societies healthier*. Abingdon, UK: Routledge.

Wilson, D. (2008). The significance of a culturally appropriate health service for Indigenous Maori women. *Contemporary Nurse, 28*(1-2), 173-188. doi:10.5172/conu.673.28.1-2.173

Wilson, D., & Barton, P. (2012). Indigenous hospital experiences: A New Zealand case study. *Journal of Clinical Nursing, 21*(15-16), 2316-2326. doi:10.1111/j.1365-2702.2011.04042.x

Wilson, D., & Hickey, H. (2015). Māori health: Māori- and whānau-centred practice. In D. Wepa (Ed.), *Cultural safety in Aotearoa New Zealand* (pp. 235-251). Melbourne, Australia: Cambridge University Press.

World Health Organisation (WHO). (2011). *10 facts on health inequities and their causes*. Available from: http://www.who.int/features/factfiles/health_inequities/en/

World Health Organisation. (2013). *The World Health Report 2013.* Luxemburg: World Health Organisation.

World Health Organisation. 2017. *Constitution of World Health Organisation Principles*. Available from *http://www.who.int/about/mission/en/*