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# Finding the Boundaries of Tolerance: Exploring attitudes to health illness and disability

#### Athena Gavriel

Stigma, silence and little in-depth research into Hellenes' worldviews and practices regarding health, especially mental health, illness and disability, were catalysts for interpretative mixed method research, primarily of Hellenes in Aotearoa-New Zealand (NZ) with some resonance for Hellenes elsewhere (Gavriel, 2004). Being a NZ-born Hellene and a mental health nurse allowed a unique inside researcher position for indepth inquiry. Part of these findings form the basis of this discussion, which argues for meaningful changes or solutions to occur, Hellenes need to acknowledge and make overt often covert, health-related worldviews: attitudes, values, beliefs and behaviours, practices, pre and post migration experiences and concerns. These mechanisms position individuals, including or excluding them from relationships or groups with sanctions and laws maintaining these positions or shifting them. This paper will also identify and examine ensuing boundaries of tolerance to inform the reader about barriers to accessing help and treatment or services, which ultimately affect wellbeing.

## Introduction

Worldviews affect individual and collective responses to health, illness and disability, hereafter referred to as health-illness. Two decades ago the media exposed conditions at the mental institution on Greece's Leros Island (Gabriel, 1990). Residents' poor treatment and living conditions highlighted attitudes towards Hellenes with mental illness and disabilities, reflecting the degree of stigma: the shame, disrespect and marginalisation they experienced. Consequently, this situation stigmatised Hellenic culture through other Greeks' and international communities' outrage about perceived backward inhumane behaviour (Carlisle, 1990; Heenan, 1993; Mertzanakis, 1994). Strutti and Rauber (1994) stated that until attitudes change, attempts to improve Greek mental health services and treatment would be slow and resisted at Leros. Indeed, problems continue in Greece, including Leros, despite the European Union

providing money and training to advance Greece's mental health services (Mental Health Europe, 2008; psi-action-en, 2009a, b; Hadjimatheou, 2009). Such attitudes and responses continue to affect NZ and other Diaspora Hellenes (Kladakis, 2009). Previous research with Hellenes identified some responses to health-illness and social conditions (Blum and Blum, 1965; Kanitsaki, 1993), such as shame and stigma in England (Papadopoulos, I., 1994, 1999; Papadopoulos, Leavy and Vincent, 2002), and Australia (Westbrook, Legge and Pennay, 1993; Retchford, 1972). Perceptions that affects of the interplay, between these attitudes and mental health-illness, lacked holistic understanding, became a catalyst for this research. A publication entitled "We are all different and the same: Culture, identity and mental health worldviews, wellbeing and health-illness experiences of Hellenes in Aotearoa-New Zealand" (Gavriel, 2004), considered, in-depth, the relationship between culture, identity and mental health, to inform Hellenes and other interested parties. This paper's focus presents the findings in relation to attitudes affected by mental health-illness knowledge, practices, pre and post migration experiences, and worldviews, attitudes, values, beliefs and behaviours. The main aim of this focus is to demonstrate how these attitudes act as mechanisms to position individuals, including or excluding them from relationships and social groups. In addition, this paper examines the ways in which societal, cultural or religious sanctions and laws work to maintain or shift such positioning. It will explore boundary markers of tolerance created by these individual and societal responses to such important issues as health-illness states, over viewing related barriers and changes beginning to occur. This paper further suggests the relevant questions and strategies to consider. The author proposes that for meaningful or lasting changes to occur, it is necessary to acknowledge and understand existing individual and collective health-illness responses, which influence decisions to use health services and/or opportunities to improve health. Open discussions such as this serve to inform people, dispel myths or fears, and create spaces or processes for change, thereby minimizing barriers for Hellenes, wherever they live. Any culture or society contains diverse worldviews influenced by personal and external factors and experiences. Therefore, whilst some might identify with the worldviews or responses presented here, making assumptions or creating stereotypes could create barriers or miscommunication for other Hellenes.

## An outline of the study

New Zealand's Hellenes began arriving in the 1800s as seekers of fortune. Most came as chain migrants and refugees, in the period 1920s–1970s from Greece and countries of its Diaspora, and from Cyprus, in the 1950s–1970s period. Collection processes for NZ ethnicity data make accurate statistics difficult to ascertain for its 4,000–6,000 Hellenes, who comprise about 1% of the population, with two-thirds living in the Wellington Region. NZ-Hellenes' experiences sit within the NZ cultural context. Some liken the nature of these small, isolated, reasonably close-knit communities to a Greek village.

This interpretative mixed method study explored some Hellenes' culture, identity, worldviews, health-illness practices and experiences. The researcher's insider roles and experiences as a NZ-born Greek and Cypriot mental health nurse, provided an informed unique understanding of the topics and cultures involved. Data collection included participant-observation, maintaining a reflective journal and 20 semi-structured in-depth interviews with five overseas-born and five first-generation NZ-born participants, originating from Greece, Cyprus, Russia, Romania, Turkey and Egypt. They equally represented both genders, various marital status, aged 20 to 96 years, all self-identified as Hellenes, a belonging they described as "a sense of feeling Greek... a shared identity and shared culture of Greek, Cypriot and Hellenic Diaspora communities" (Gavriel, 2004:12). The lack of published research has led to further inquiries to ascertain any shared themes and issues with Hellenes elsewhere, using, for example, email questionnaires and conversations with overseas Hellenes. Secondary sources have included books, newspapers, films, documentaries and academic journals. Methods of narrative, story, poetry, metaphor, cultural symbols and photographs have honoured people's worldviews and experiences, to reveal diverse and similar voices, to retain confidentiality, authenticity and to convey understanding of sensitive, stigmatised areas.

Findings have covered a range of topics: knowledge, beliefs, practices and experiences about health-illness experiences and comprehension of health systems, professional and family roles, changing attitudes, barriers to accessing help or services, and the ascertaining of compliance with NZ health policies for ethnic service users. Socio-cultural areas, relating to mental health and wellbeing, have covered culture and identity, its manifestation in NZ-Hellenic communities, life histories, and immigrant and refugee resettlement experiences. The values and attitudes explored, have included religious, spiritual and superstitious beliefs and practices, interpersonal relationships, family, community, sexuality, education and employment. Some concerns that were raised have included abuse, suicide, divorce, intergenerational issues, conflicts or differences in culture, values and worldviews.

## **Health Attitudes Reflect Worldviews**

The research has identified many factors that contributed to forming health-illness attitudes. This includes primary socialisation of beliefs, practices and experiences that occurred through family and significant others and secondary socialisation that evolved through school, work, friends, other groups and cultures in the wider society. Participants' definitions and beliefs about health-illness presented diverse physiological, psychosocial, spiritual and environmental facets. Examples of being healthy included respect for one's body, good diet, exercise, everything in moderation, and minimising stress. Perceived causes of physical and mental ill health were physiological, including some beliefs that non-genetic conditions were in the blood or the genes, psychological, or spiritual, due to curses or moral ills. Participants believed

cultural identity was essential for wellbeing because it provided a sense of belonging and contributed to self-esteem, as did a good work ethic, education, and caring about others and one's community. Traditional health knowledge and healing practices were found to be diminishing. Greek Orthodoxy has continued many associations with health-illness through fasting, prayer, pilgrimages and tamata (votive offerings) to protect health or cure people. Research has confirmed beneficial effects of Orthodox fasting diets (Psaltopoulou, Naska, Orfanos, Trichopoulos et al., 2004). Moral attitudes, such as being compassionate, non-judgemental and refraining from self-abuse or abusing others were also considered influential. Sometimes people interviewed thought Christianity or education would change commonly held beliefs about magic and superstition such as Matiasma (the evil eye), curses, omens and the significance of dreams. Some Christians interviewed believed they should not partake in activities considered magic, whilst others thought supernatural phenomena coexisted with Christianity, and Magi or magicians' healing knowledge and abilities were God given.

## **Finding Boundaries of Tolerance**

Participants' perceptions of Hellenic attitudes formed two differing clusters: village versus urban, uneducated versus educated, closed-mined versus open-minded. They associated narrow closed-minded worldviews with people from villages; they were seen as naive, ignorant, intolerant or fearful, whereas open-minded people were viewed as urban, worldly, educated, compassionate, understanding and tolerant. However, the research undertaken, occasionally found inconsistencies with these perceived clusters. For example, people from villages sometimes expressed open-minded and compassionate worldviews. Education did not necessarily change beliefs, demonstrated by a NZ-born woman's surprise that another NZ-born educated friend believed in the evil eye, a belief she associated with ignorance. Participants' personal experiences, their observations made about different countries or cultures, and individual understandings of Hellenic culture's legacy, also influenced worldviews. Opposing tensions that formed the edges, shaping boundaries of tolerance, included: survival versus victimisation; honour versus shame; openness versus secrecy; perfection versus imperfection; control versus lacking control; compassion, tolerance versus intolerance, rejection; and community versus institutional life. All these tensions interconnected and influenced each other.

Participants often considered themselves survivors, using images, icons, heroes, myths, legends, stories from ancient and modern Hellenic history and religion, as examples of strength, wisdom and survival. They used these to help overcome challenges, cultural prejudice or negative stereotypes, as a man who immigrated as a young child demonstrated:

One of the first poems I learnt at Wellington Greek school, "Who goes to school at night time" ... taught me to be Greek is to really value something. We are survivors. It's a special inheritance because we are descended from people who were being oppressed ... I was

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taught to value myself, who I am culturally, and so were my brothers, sisters and cousins. The secret schools and the debt the secular owes to the religious because of those times ... that's what made me proud to be Greek. It's something I can take around with me and hand on to my children. When I was small and had bad self-esteem this is what I held on to, I am important and special because I belong to this type of people (Gavriel, 2004:143).

Sometimes the Spartan attitude of survival of the fittest created an attitude that they should cope, so people did not ask for help or accept it when offered. People without survival images appeared less proactive about their health-illness. They tended to be orientated towards an external locus of control, believing life or health outcomes were more influenced by external factors such as other people, fate, chance, or luck *tihi*. A woman immigrant said:

I think they have some control over their destiny and their health. Attitude is the biggest problem, for example the extreme Greek attitude to divorce, "It was my bad luck," without realizing they've contributed ... Ti  $\theta \alpha \kappa \dot{\alpha} v \omega$ , what can I do? Is an attitude of ignorance, being stuck. People don't know how to find things out or help themselves ... Greeks' attitudes tend to be more fatalistic. They aren't so much into self-help, they'd ... just grin and cope, instead of being proactive. They'd expect health professionals to fix them (Gavriel, 2004:139).

#### Another NZ-born commented:

My mother's idea of being cured is to have something done to her by the doctor, like pills or injections. She's been asked to change her lifestyle, doesn't know why. Now sees the problem is beyond help, only with drugs (Gavriel, 2004:139).

Honour and shame had individual and collective affects. With respect to honourable actions, people accepted public acknowledgement of their achievements, but believed self-praise or envy could attract the evil eye. It was believed that honour brought elevated status, making the recipient feel accepted, successful and included. Shameful actions or situations, by comparison, caused people to keep their circumstances private, creating reluctance about others knowing, even sometimes, very close family and friends. Such lowered status left them feeling rejected, a failure and isolated (Gavriel, 2004:132).

### So What Is Shame?

The water is muddy and deep, Churned by the waves of time. Waves of passion, confusion, despair, Waves of embarrassment and fear.

Sometimes in their white frothy tips
There is a sense of pure logic
Other times in the muddy waters, churned and turbulent
There is just a feeling of dirt that cannot be shaken off.
A want to run and hide

To curl up, not face the world, Nor anyone in it.

(Athena Gavriel, 1997/2004:132)

This poem crystallises collective feelings Hellenes had experienced from stigma, seeing its nature as contamination, weakness or imperfection, again inferring cultural intolerance, reminiscent of warrior states like Ancient Sparta which eliminated such people. They used *dropi* to refer to shame, describing people's names becoming *homa*: mud or dirt. Secrecy often prevailed in stigmatising situations because the person, their family, sometimes friends or community felt shame collectively, creating concern about others' reactions. Participants gave examples of situations triggering acts of revenge to restore honour to an individual and/or family after rape, incest or other demeaning actions that caused shame, embarrassment or dishonour. Fear of blame or shame could silence victims, allowing abuse to go undetected, demonstrated by a woman not telling anyone, including family, about her husband's violence, until years after the divorce.

Lacking self-control was seen as shameful, whether causes were physical, such as being drunk, incontinent or due to debilitating illnesses like cancer or AIDS; or whether causes were mental, for example, through emotional outbursts, mental illness, impaired memory or reasoning. Tensions from perfection versus imperfection led to concern and stigma about physical or mental disabilities, especially visible ones. This created apprehension about individual and family members' eligibility to marry or become a parent. Genetic conditions generated fears of transmitting "faulty" or "bad" genes to offspring: for example, a person's limp prevented marriage because of family concerns children would inherit it. Migrants reported occurrences of teasing, bullying or pitying of eccentric or disabled people in Greece and Cyprus, although their community and family usually accepted or tolerated them. However, once diagnosed with a mental illness, fears of people becoming dangerous often led to institutionalization. Pre migration experiences or beliefs shaped preconceptions and attitudes towards health-illness in NZ. A caring spirit meant NZ-Hellenes usually struggled to look after ill, disabled or elderly relatives at home rather than place them in an institution.

Marginalisation positions a person on the edges or in between spaces of a culture or society. Greece's Meteora Region named after meteora, heavenly bodies, and meteoro, something aloft or suspended (Gavriel, 2004:8), generated symbols and metaphors used in the study. The terrain reflects marginalised or unusual experiences sick or vulnerable people have when they encounter alien worlds, systems or services. Meteora's monks, who previously lived in caves up in the cliffs, still live in monasteries built centuries ago, upon pinnacles, to escape Ottoman persecution. This positive example of marginalisation and adaption to life's challenges, symbolizes strength and survival in the face of adversity.

### The edge of the edge

At the place of the tides,
Where water meets sand,
Not sea nor land.
I, we stand.
At the dawn and the dusk,
Where earth, fire, air and sea,
Meet in their splendour.
Neither day nor night will eternally surrender.
The strong and the weak,
Seek a place to be.

(Athena Gavriel, 1995/2004:7)

## **Barriers**

Previous research consisted mainly of surveys in other countries, revealing Hellenes underreported stigmatising mental illnesses or disabilities, creating difficulties for diagnosis and treatment (for example, Adamopoulou, Garyfallos, Bourea and Kouloumas, 1990; Boardman, Bilankas, Zouni and Bouras, 1992; Elton, Patton, Weyerer, Diallina and Fichter, 1988; Garyfallos, Karastergiou, Adamopoulou, Moutzoukis et al., 1991; Mavreas and Bebbington, 1988). This research (Gavriel, 2004) provides some insights into barriers of communication, values, attitudes, knowledge and practices that can prevent people from seeking or accepting help or treatment. Clear, understandable communication is necessary to overcome language barriers, convey information about health-illness conditions, systems and services. When encountering health services, NZ-Hellenes often felt isolated, usually relying on family for support and often interpreting. Information about health and NZ health services, mainly in English, left many migrants uninformed about these matters and their rights as health consumers (Health and Disability Commissioner, 1996). They had little information on how to lay a complaint and many did not know that assistance was available, for example, to access interpreters or advocates. Knowledge of and beliefs about healthillness, health systems, services, roles or expectations of health professionals and family as healers and carers, varied with personal experiences and ability to understand English. Due to their expertise, many expected health professionals to direct treatment, not offer choices. People declined help or care for diverse reasons. For instance, a survivor's attitude meant people would bear pain or discomfort, deciding not to seek or accept help, because they felt they should deal with their illness or disability unassisted. If necessary, help was the family's role. One participant stated, "Your family is your social services" (Gavriel, 2004:203). The immigrant generation especially acted as if they were still guests in the host country, feeling they should not complain about services received, or burden society by expecting help. Mistrusting outsiders meant seeking external help for care, including from health professionals,

was often a last resort. Modesty was another frequent reason for refusing help with personal activities like bathing.

Many experiences revealed clashing cultural beliefs and values, creating culturally unsafe situations and tensions with mainstream NZ mental health professionals. For example, Hellenes usually perceived professionals encouraging a divorce or encouraging children to go flatting, as stigmatising actions, implying unhappy or pathological family dynamics, rather than liberating individuals. Secrecy and silence surrounding stigmatising situations conflicts with western health ideologies that openness and social inclusion will break down stigma. Findings also supported research by Zacharakis, Madianos, Papadimitriou and Stefanis (1998) that these attitudes, plus religious condemnation, prevented people seeking help with suicide. Most were unaware of the church's sympathetic position regarding suicide and mental illness (Orthodox Forum, 2001). Shame often prevented disclosure to family or mental health professionals about any abuse: rape, incest, domestic violence, alcohol, drugs and other traumas relevant to forming an accurate diagnosis or treatment. This distrust also created reluctance to talk with professionals about sensitive issues and barriers to treatments using individual or group talking therapies. Another case reveals a service's intolerance to different needs for an elderly diabetic NZ-born Greek woman receiving daily treatment for leg ulcers. Nurses' previous refusals to accommodate times for church services made her family request, well ahead, for early treatment the day of her father's one-year memorial service. They explained its religious and cultural significance, her roles in preparing special food and requiring early attendance at church for rituals to begin, with lateness showing disrespect. Although the service agreed to the request, the day before, the treating nurse said she was not coming early, causing debate about the request's importance until the woman referred to the service's statement about respecting cultural and spiritual needs. The nurse reluctantly agreed to come, saying she would report the woman to management, leaving her feeling distressed and vulnerable. The next day the nurse arrived early, making angry comments, again upsetting the woman who believed the discord would disturb her father's soul. The woman felt disrespected and demeaned by the service's dismissal of family concerns about the incident. Refusing to use the service again caused many hospitalisations (Gavriel, 2004:220-221).

## **Changing Attitudes**

Socialisation, experiences, assumptions and stereotypes maintain attitudes. Findings that health-illness attitudes change through socialisation, experiences, exposure to other cultures, worldviews, systems or treatments, new technology and medicine (Gavriel, 2004), supported research by Papadopoulos, Leavy and Vincent (2002). These factors affected attitudes and decisions to access help from NZ social and health services. With NZ-Hellenic women's changing roles, families face dilemmas when caring for sick or aged members at home are influenced by competing considerations from careers, work, financial demands, and less family support through migration.

Health education in schools and public campaigns about health-illness, social issues, services and supports appear to be changing some younger NZ-Hellenes' attitudes. This change in attitude is also influenced by an increased receptiveness to the English language, mainstream culture, and exposure to different services and therapies. For instance, some younger participants had used counsellors recommended by people they trusted, indicating they would use them again or recommend them to others, if needed.

One cannot assume being born or socialised in another culturally different society will change attitudes. For example, this research supports American findings that beliefs in Matiasma have continued in generations after migration (Tripp-Reimer, 1983; Gavriel, 2004). However, participants have indicated that traditional health and healing knowledge and practices, usually transferred from mother to daughter, had declined after immigration to NZ, due to women not learning practices before migration or post migration and having no one available to pass on skills. The decline had also been influenced by Hellenic men marrying outside the culture and/or specific healing herbs or other items becoming unavailable. Furthermore, some women did not pass on the knowledge because they saw practices as archaic or unacceptable in the host society, and/or considered modern medical practices more accessible, affordable or beneficial. Family and friends continued to retain roles fostering an environment of love, encouragement and care for healing to occur. NZ-Hellenes remained reluctant to place loved ones in institutions. If such care was necessary, they believed they visited loved ones more than Anglo-New Zealanders, except in mental institutions.

## Accessing health services

Developing accessible health services that reach the targeted audience requires Hellenes, health providers and educators to understand cultural attitudes that create barriers to some approaches. People often stated that public meetings arranged within the Hellenic community to discuss or inform people about stigmatising health issues would have poor attendance due to concerns about gossip or others assuming that their presence indicated they had problems. Concerns about gossip sometimes deterred people from talking openly about their circumstances to health professionals or with interpreters present. Health information, education, public health campaigns such as NZ Mental Health Commission's 2004 "Like Minds, Like Mine" to reduce stigma about mental health-illness, need to be accessible in Greek and various forms: DVDs, CDs or pamphlets, to take away discreetly or anonymously, consider in private, so people can seek help.

In conclusion, Hellenes everywhere need to have open discussions to understand and consider the implications of their personal, cultural and societal worldviews and responses to health, particularly mental health-illness states that create stigma and shame collectively for individuals and families. This research (Gavriel, 2004) has complemented other Hellenic health research and increased understanding by

describing and exploring attitudes, underlying rationales and ensuing health-illness responses, survival mechanisms and barriers to seeking help or treatment. People sometimes include genetic, spiritual, moral or mental weaknesses or transgressions as causes of illnesses and disabilities, therefore others actions and reactions can affect their social status and marginalise them. The retention of worldviews across generations and countries, plus memories of images and experiences, affects the socialisation of attitudes and beliefs. These are unlikely to change without exposure to experiences, attitudes, images or beliefs that facilitate change. Through increased understanding about the nature of attitudes, practices and boundaries of tolerance, the mindset of professionals and communities can find a way forward to change, improve services, and reduce the stigma and shame that creates an air of secrecy, silence and isolation, affecting mental wellbeing further.

### Lonely Song

I heard you cry
That song of sorrow
In the wilderness.
Did you hear me sing back?

(Athena Gavriel, 1995/2004:230)

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