Discussions in Disability

DISABILITY AND ETHNIC MINORITIES

University College Dublin
Centre for Disability Studies
UCD School of Psychology
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“Navigating Health Systems”

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Born 14th September 2008
Departed this life 21st April 2015
What you may have seen or heard?
Global movement of people has resulted in a shift in thinking…

Where are YOU positioned as a client, health professional, manager, organisation in this process?

National immigration law is often the arena where human rights and national self interests clash and the principle of promoting the best interests of vulnerable groups can be over looked.
Migration means of access...

- Immigration Processes – Visas, work / study permit, others
- In the main - rigid administrative system (? Overly bureaucratic, complex / lengthy, ?? Person centred?? - Economy / society
- **Protection System**
- 6 ways of getting access into the Irish protection system:
  1. Existing Refugee Programme – “Programme Refugees”
  2. Medical Programme Refugees
  3. “Ordinary” Asylum Seekers
  4. Family Reunification Programme / other mechanisms
  5. No status – e.g. ‘undocumented’
  6. IRPP programme – “EU Relocation”

Responding to migration and ‘ethnic minority’ health issues....
All people (Staff & patients/clients) approach encounters with their own unique attitudes, communication, behaviour, expectations of services, expected outcomes, beliefs about illness & types of treatment.

Cross-cultural health / social care situations may be challenging due to: fear, embarrassment, lack of clinical and cultural knowledge, pre-occupation with medical condition, theoretical models, time constraints, communication difficulties, interpersonal issues e.g. trust,
FACT

- Language & cultural factors combine to produce a failure to communicate and frustrating even dangerous results.

- To offer culturally competent care requires being open to the experiences, expectations, perceptions, and realities of various individuals & communities.
Dignity

‘Quality of being worthy of respect’
‘self-importance’
‘pride’ ‘self-esteem’
self-respect’
Understanding Migration… asylum / refugee population…

- ‘Push & Pull’ Factors
- Socio-Political Factors

- Experiences prior to arrival, en route, current – regardless of migrant status - Access to “health care” prior to arrival (type, frequency, cost)

- Cultural adaptation / integration

- Physical /Psychological

- Biological Variations - *ethnic minority epidemiology*

- At risk sub-groups – *life-limiting illness, disability, elderly, unaccompanied children*,
Understanding migration....asylum seekers / refugees

• Loss & Bereavement
• Trauma / Torture
• Security / Safety / Trust
• Access to services – health & illness – cultural interpretations / health help-seeking behaviours
• Effects of living in and navigating the asylum process
• Future Prospects – access to specialist services, community peer supports, shared understandings of experiences – staff and organisations.
Understanding the complexity...ethnic minorities and disability...concept and context.

♦ Intersectionality - common experiences – challenges and opportunities

♦ In general ambiguity exists in the use of language & terminology within the discourse of ethnic / cultural diversity and health and disability sectors / disciplines – at practice and policy level

♦ Categorizations – by whom / what / FOR WHAT PURPOSE? (administrative, social, cultural, language, medicalization immigration status)

♦ Ethnic minorities, migrants, refugees NOT homogenous groups – terminology / definitions - attention to the diversity ‘within’ and ‘between’
Understanding the complexity….

♦ Intersectionality (contd).
♦ Disability increasing globally as a consequence of civil conflicts, war, natural disasters – impact on MRDPs - who become asylum seekers.

♦ Labelling, Stigma, Taboo, “othering”
♦ Prejudice and discrimination (Direct / Indirect /Conscious /Unconscious)

♦ Entitlements - Basic Needs – ‘who is entitled to what? 
♦ In the first instance are those people affected by or living with ‘disability’ coming forward for support, advocacy, services etc?

♦ WHAT IS THE IMPACT ON CLIENTS, HEALTH / SOCIAL CARE STAFF / SERVICES……SOCIETY ?
Disability and ‘ethnic minorities’ cultural understandings… (Helman 2007)

- The ‘able’ body and ‘disabled’ body
- Disability versus Impairment
- Disability and Stigma
- Theories of causation of Disability
- Positive Aspects of Disability

- Wide variations within and between different social and cultural groups.
- Narrow definitions - Shift from individual (physical impairment/medical) to social pathology.
- Social stigma associated with disability in some cultural groups… ‘normal life – pathways’ (milestones, rituals) become interrupted or not full-filled – what is acceptable as a potential wife / husband, home maker / provider?
Health and social care provision….

WE need to look at ourselves & how we do things (plan, practice, deliver services)

♦ Socio-Cultural
♦ Political / Legal
♦ Organisations / Systems
♦ Professional Education
♦ Leadership / ‘Ignorance’

“HEARTS & MINDS”

Cultural competence
Partnership +
Empowerment =

Equality

“The elephant in the room”
(ETHNOCENTRISM)
Health sector considerations...

- Awareness of our own and other’s deep cultural, ethnic and spiritual frameworks of being in the world. Culture as learned.

- Acknowledging diversity of worldviews in understandings & explanations of wellbeing, illness, inherited conditions, behaviours, treatment, life-ways etc.

- Significance of language as an expression of culture (not all words / concepts are transferable)
• Health care anthropologists speak of “symbolic anatomy” within traditional health systems e.g. Chakras (Hinduism, Buddhism), bhutas (5 earthly / universal elements) in Indian Ayurvedic, Yin and Yang (hot / cold - male / female) in Chinese.

• Harmony between human body and the universe (Cosmos) - religious, cultural, social rituals

• Balance and imbalance - health maintained by the harmonious balance between two or more elements or forces within the body. To a variable extent this is dependent on external forces such as diet, environment, and /or supernatural agents.

• Causation of illness, disease, disability, morbidity – varies across and within ethnic / cultural groups and the subsequent treatments / cures / rituals accessed.

• Western bio-medical health care and systems mostly derived from scientific models, paternalistic, ethnocentric - may see these approaches as merely symbolic – mystical metaphors that bear no relation to physical reality.
Cultural competence in nursing & primary healthcare

♦ ‘The ability to function effectively in the context of cultural differences’ (CCHCP 2001)

♦ This is informed by attitude, motivation, knowledge and skills

♦ Cultural competence is **not** about knowing all there is to know about a particular culture

♦ Cultural competence is NOT an end point – it is a continuous process of learning and development – which is constantly evolving in response to new cultural and health care contexts (PTT 2006)

♦ Cultural Competence Continuum – (Cross et al 1989)

♦ “Always becoming…” (Camphina-Bacotte 2002).
Transcultural Nursing (TCN): (Leininger, M.)

Madeleine Leininger’s Transcultural Nursing
The Sunrise Enabler to Discover Culture Care Sunrise Model

Influencers

Culturally congruent care for health, well-being or dying

Nursing care decisions and actions

Cultural care preservation & maintenance
Cultural care accommodation & negotiation
Cultural care repatterning & restructuring

Influences

Holistic health/illness/death

Care expressions, patterns & practices

Educational factors

Economic factors

Political & legal factors

Cultural values, beliefs & lifeways

Religious & philosophical factors

Technological factors

Kinship & social factors

Cultural & social structure dimensions

Worldview

Individuals, families, groups, communities, or institutions in diverse health context of

Generic or Folk Care

Nursing Care

Professional Systems

nurseslabs
The Papadopoulos, Tilki and Taylor Model for Developing Transcultural Nursing Competence

**Cultural Awareness**
- Self awareness
- Cultural identity
- Heritage adherence
- Ethnocentricity
- Stereotyping

**Cultural Competence**
- Assessment skills
- Diagnostic skills
- Clinical skills
- Challenging and addressing prejudice, discrimination and inequalities

**Cultural Knowledge**
- Health beliefs and behaviours
- Ethnohistory / Anthropological understanding
- Sociological / Political understanding
- Psychological and Biological understanding
- Similarities and variations

**Cultural Sensitivity**
- Empathy
- Interpersonal / communication skills
- Trust
- Acceptance
- Appropriateness
- Respect

### Characteristics, determinants and Perceptions of Race, Ethnicity and Culture (PTT 1995 / 2006)

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<thead>
<tr>
<th></th>
<th>Characterised by</th>
<th>Determined by</th>
<th>Perceived to be</th>
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<tbody>
<tr>
<td><strong>‘Race’</strong></td>
<td>Physical appearance</td>
<td>Genetic ancestry</td>
<td>Permanent (genetic / biological)</td>
</tr>
<tr>
<td><strong>Culture</strong></td>
<td>Behaviour / attitudes</td>
<td>Up-bringing choice / learned / socialised</td>
<td>Changeable (assimilation / acculturation)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td>Sense of belonging Group Identity (physical / biology)</td>
<td>Social Pressure Psychological Need</td>
<td>Partially Changeable</td>
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PTT Model for Developing Cultural Competence - Underpinning Values used in Migrant Health
(Papadopoulos Tilki Taylor 1998)

- Human Rights
- Socio-Political Systems
- Intercultural Relations
- Human Ethics
- Human Caring

“The failure to provide culturally appropriate services is not always deliberate but is underpinned by ethnocentricity which assumes people of other cultures find mainstream provision acceptable and effective”

Tilki 2006
Cultural Competence in Practice

General Information
- Current affairs / media
- Geography
- History / Heritage
- Languages / Dialects
- Communication styles – verbal / non-verbal
- Ethnic Groups
- Religion / Spirituality
- Socio-economic
- Perceived Roles - gender, age, marital status, education, professionals

Health Specific
- Cultural Health Beliefs
- Cultural Types of care: *Popular, Folk / Traditional, Professional*
- Sick / Care Behaviour
- Ethnic Biological Differences
- Pharmokenetics
- Healthcare relationships: prescribed roles / Prof. / Lay
- Involvement in Care / decisions / Patterns e.g. consent, families role in ‘life’ / hospital care etc
Cultural Competence...some practicalities....specific issues re: disability?

- Modesty / Privacy
- Communication / language / gestures / expressions
- Touch Practices / Proxemics / Space
- Perceptions of Time & Date – different calendar
- Diet / food / nutrition / medications / pharmacology
- Cultural manifestations - Reactions to Pain (Psych / Physical)
- Understanding of ‘the human body’ / causation
- Understanding illness, disability, ‘misfortune’ (Illness V’s Disease Models)
- Folk Understandings & popular beliefs - healthcare systems
- Rituals & Milestones :Birth, naming, coming of age / independence, marriage, death, etc – impact for disability
- Childrearing Practices: Parenting / Discipline
- Value of Play / Education / Careers
- Prescribed Roles – gender, age, class, (intergenerational issues)
- Religion / Faith
Cultural Competence in Community Public Health Nursing (Boyle 2014)

- Experiencing change in population
- Racism
- Focus on ‘Difference’
- Building relationship and communication
- Professional Preparation and Support

- Overall nurses were interested and ‘aware’ - - doing enough ‘just to get by’ (as per CCAT / PPT)
- Mostly Practice / experiential knowledge - undervalued / lacking confidence
- Personal, professional and organisational barriers led to tension and ambiguity - conflict and complacency
- Unfamiliar with TCN / CC theory
Why do we do what we do? How do we respond?

Obligations:

- Moral & Ethical
- Professional
- Statutory & Legislative
Useful references / Bibliography:


Useful references / Bibliography:


Useful Sources of Information

- www.icn.ch
- www.unhcr.org
- www.healthequity.ie
- www.tnn.ie
- http://www.europeantransculturalnurses.eu
- http://www.hpsc.ie/A-Z/SpecificPopulations/Migrants/
- www.hse.ie

- Further statistical information on asylum system / refugees.
  - www.inis.gov.ie
  - www.ria.gov.ie
  - www.integration.ie
  - www.equality.ie
  - www.mrci.ie
  - www.unhcr.org
  - www.pavepoint.ie
  - www.irishrefugeecouncil.ie
  - www.cso.ie (Central Statistics Office)
Go raibh míle maith agaibh!

**Contact Details:**

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