Overview of equality and health inequality issues and dementia

Jo Moriarty
Social Care Workforce Research Unit
‘By 2015 every person with dementia will be able to say’

‘I get the treatment and support which are best for my dementia and my life’

‘I know what I can do to help myself and who else can help me. My community is working to help me to live well with dementia’

‘I wanted to take part in research and was able to do so’
There are parts of the country where it takes six months to get a dementia diagnosis, which is absolutely scandalous. I want to get to a situation where the average across the whole country is no more than six weeks

Jeremy Hunt, interview in The Telegraph, 27 February 2014

Government plans to improve regional variations in screening
Where does this leave us?

- Prime Minister’s *Dementia Challenge* recognises variations in access to good dementia support
- Focus on regional variations in screening but we need more ‘hard’ evidence on other aspects
- Findings presented here will be familiar but offer a framework for discussions throughout the day
Equality Act 2010

- Rationalised existing legislation
- Some new provisions
- Nine ‘protected characteristics’
  - age
  - disability
  - gender reassignment
  - marriage and civil partnership*
  - pregnancy and maternity*
  - race
  - religion or belief
  - sex
  - sexual orientation

Equality and health inequality issues in dementia

7 May 2014
Age

• Risk of dementia increases with age
• But increasing numbers diagnosed before age of 65
  • Difficulties getting a diagnosis
  • Increased stigma
  • May face different issues (e.g. employment, young children)

Equality and health inequality issues in dementia

http://www.youngdementiauk.org/

7 May 2014
Disability

- Office for National Statistics data shows variations by age, region, ethnicity, income
- Concerns about comorbidities long-term conditions
- ‘Diagnostic overshadowing’?

ONS data on disability 2012

- Longstanding illness or disability
- Limiting LSI

Equality and health inequality issues in dementia

7 May 2014
Dementia and learning disability

- Better life expectancy
- Higher prevalence of Alzheimer’s disease among people with Down’s syndrome
  - Also higher risk of other health conditions
  - Reported incidence varies but as much as 25% in over 60s (Kozma, 2008)

Joseph Rowntree Foundation & University of Edinburgh DVD
Gender

- More women than men have dementia
  - May reflect different life expectancy
  - AD/VaD similar for men & women until extreme old age (Ruitenberg et al, 2001)
  - Others say different prevalence rates (e.g Roberts et al, 2012)

Image from Casual Fridays blog
Sharpest differences in care homes?

- More women than men live in care homes
  - Women tend to marry men older than them and to live longer
- Poverty rates worse among ‘single’ women households
- About 80% social care workforce are women

Image Scottish Parliament website
Sexual identity

- Neglect of lesbian, gay, and bisexual (LGB) sexual identities in research on dementia
  - Experiences of discrimination as carers (Price, 2008)
- More research with older LGB people (Guasp, 2011)
  - Previous experiences of stereotyping and prejudice major barriers to using services
    - ‘de-gay-ing’ home before visits

Image from Alzheimer’s Society website
 Possible inequalities

• Barriers to using health and care services
• Higher proportions of older LGB people living alone (Guasp, 2011)
• Higher proportions of older LGB people living in poverty (Uhrig, 2013)
• US research shows effects on social support mixed

Equality and health inequality issues in dementia
But beginning to be addressed

- Dementia Engagement and Empowerment Project (DEEP) has funded new project in Birmingham
- ONS has been testing questions on sexual identity in Integrated Household Survey (2012)
Gender identity

• Reminder that gender identity and sexual identity not the same
• ‘Binary’ gender distinctions do not reflect many people’s perceptions of self
• We don’t routinely ask whether people self identify as transgender/intersex/or other identity
• Can surmise there is population of older people who transitioned in 1970s but no data
Marginalised

• Differing views as to advantages/disadvantages of LGBT grouping
• Evidence base extremely small for everything, let alone dementia
• Research with transgender people suggests that many people have had experience of discrimination which influences ‘help seeking behaviour’ in old age
Some US research

- Conference paper using data from International MetLife Survey on Preparation for Aging in Trans-Identified Populations (McFadden et al, undated)

- Older transgender adults (aged 60 and over) very concerned about developing dementia
  - Concerned about intimate care
  - Concerned they will be treated in ways not congruent with gender identity
Ethnicity

- Present later to services when dementia is more severe (Mukadam et al, 2011)
- Knowledge about dementia appears to be less (Seabrooke & Milne, 2009)
- Stigma may be greater (LaFontaine, 2007)
- Carers may experience particular difficulties (Bowes & Wilkinson, 2003)
Projected increase in numbers of BAME people with dementia

2013 - 25000
2026 - 50000
2051 - 172000

Equality and health inequality issues in dementia
Religion

• In some instances may be more appropriate to look at ethno-religious groupings (Hills et al, 2010)
  • But generally reported in terms of ethnicity

• Risks of stereotyping
  • In 2001 Census Chinese people were the ethnic group most likely to say they had no religious affiliation
Socio-economic status

- Research in this area is mainly from the US
- Suggests there are risk factors related to socio-economic status
  - Education as a ‘protective’ factor?
  - Poorer physical and mental health throughout the life course?
Conclusions

• We have multiple identities so important not to look just at one aspect of ourselves
• Very limited data looking at interactions between different protected characteristics
• Review for Age UK (Moriarty & Manthorpe, 2012) showed data on many characteristics is not collected or not reported
• Considering these factors is an essential step in delivering more person centred dementia care
The Social Care Workforce Research Unit receives funding from the Department of Health Policy Research Programme. The views expressed here are those of the authors and not the Department of Health.
Ethnic Identity and Cultural Diversity in Dementia Care: a Person-Centred Approach

Dr Karan Jutlla
Senior Lecturer
Association for Dementia Studies,
University of Worcester
The National Dementia Strategy (2009)

• A five year plan with the core aim to develop services that ‘meet the needs of everyone, regardless of their age, ethnic group or social status’

• An informed and effective workforce
Key points

• ‘Meet the needs of everyone’: understanding communities

• Translating this into dementia care

• Equality and Diversity is about being person-centred.... isn’t it?
Understanding Communities: Ethnic identity & cultural diversity

- Whilst there are similarities across different ethnic communities, there are also differences both within and across communities based on:
  - Religion
  - Language
  - Migration experiences
  - Caste
Caste within the Sikh population in rural Punjab fit into a hierarchy comprising four broad categories. Similar across other South Asian communities (Ballard and Ballard 1979; Kalra 1980):

1. **Brahmins and Khatris** - high rank priestly class who traditionally acted as warriors to the Gurus. They comprise approximately ten per cent of the rural population of the Punjab.

2. **Jats** - the ‘landowners’ and ‘farmers’ and comprise approximately 50 per cent of the rural population of the Punjab.

3. **Craftsmen and service caste** - comprise approximately 15 per cent of the rural population, of whom the *Ramgarhias* (carpenters) are the largest group.

4. **The ‘untouchables’** - comprise approximately 25 per cent.
### Cultural Diversity Illustration

<table>
<thead>
<tr>
<th>Caste</th>
<th>Punjab</th>
<th>East Africa</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Sikhs Muslims</td>
<td>Sikhs Muslims</td>
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<tr>
<td></td>
<td>Hindus</td>
<td>Hindus</td>
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<td><strong>language</strong></td>
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<td>2</td>
<td>Sikhs Muslims</td>
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<td>4</td>
<td>Sikhs Muslims</td>
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<tr>
<td></td>
<td>Hindus</td>
<td>Hindus</td>
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</tbody>
</table>
Segregation or Inclusion?

• ...Let’s imagine a specialist service
## Migration and Dementia

### Key Historical Events

<table>
<thead>
<tr>
<th>Sikh</th>
<th>Muslim</th>
<th>Hindu</th>
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<tbody>
<tr>
<td>1947 India</td>
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<tr>
<td>1983 India</td>
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<tr>
<td>1960s UK</td>
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<tr>
<td>Others...</td>
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</tbody>
</table>
Person Centred Guiding Principles (Brooker 2007)

- Do my actions **V**alue and honour the people that I work with?
- Do I recognise the **I**ndividual uniqueness of the people I work with?
- Do I make a serious attempt to see my actions from their **P**erspective or stand point?
- Do my actions provide the **S**upport for people to feel socially confident and that they are not alone?
Person Centred Care are the processes by which service providers maintain the Personhood of those who receive their services.....

“Personhood is a standing or status that is bestowed on one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust.....”

Kitwood, Dementia Reconsidered 1997
Cultural competency

- For Gallegos et al. (2008:54) cultural competence refers to ‘the process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic backgrounds, religions, and other diversity factors in a manner that recognises, affirms, and values the worth of individuals, families, and communities and protects and preserves the dignity of each.’
Cultural competency cont...

• Involves more than having an awareness of cultural norms. It is an approach that values diversity and promotes inclusivity
• It represents a value-based perspective that recognises individuality (Gallegos et al. 2008)
• Person-centred care
Person-centred care with migrant communities

• In order to achieve ‘mutually satisfying user/provider relationships’ such people should be regarded as individuals alongside knowledge of the social and political influences on their lives rather than regarding them as members of ‘other’ groups (Mackenzie 2007:76).

• Promoting inclusivity in existing services
BAME communities

- International Community: Migration
- National Community
- Local Community
- Family
- Person
Thank you
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http://www.worc.ac.uk/discover/association-for-dementia-studies.html
Basic Facts about Population in Enfield

- 41,000 aged 65+ years; 57% female, 43% male
- 5,590 aged 85+ years; 69% female, 31% male
- 7,200 people with 2+ problems in daily living
- Two-thirds of people aged 65+ White British/Irish
- BME populations tend to be concentrated in specific wards – often more deprived areas
- 28,000 carers, 6,200 providing 50+ hours/week
- 3,050 people aged 65+ with dementia in Borough
- 1,250 with advanced dementia
- Around 70 under 65, majority with learning disabilities
Basic Facts about Population in Enfield

Proportion of 65+ Population by ethnicity (n = 41,000)

- White British/Irish: 68%
- Greek/Greek Cypriot: 8%
- Turkish/Turkish Cypriot: 3%
- White Other: 3%
- Black African & Caribbean: 7%
- Indian: 4%
- Pakistani/Bangladeshi: 1%
- Chinese/Other Asian: 3%
- Mixed: 1%
- Other: 2%

Proportion of 65+ Population by Ethnicity

Ethnic Groups - Non White (%)

by Ward

- 50 to 60.6 (5)
- 43.5 to 52 (2)
- 35 to 43.5 (5)
- 26.5 to 35 (3)
- 18 to 26.5 (5)

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Positive Things that have happened

• People’s lives more fulfilling - & disease slowed – if they get early help & treatment

• Number of people referred to Enfield’s Memory Service for diagnosis increased by 88% in a year

• Added investment in Service planned in response
Glass Half-Empty?

Many challenges remain

• In Enfield, average 42%, but wide variation across GP practices – 8% to 100% in individual practices

• Know there are barriers to access in health services & knowledge amongst specific equality groups
Enfield Dementia Action Alliance

Enfield’s response to Dementia Challenge is based on:

• Seeing problem as societal, not simply medical, one

• Coordinating & mobilising individuals & organisations – to form a partnership approach

• Focus on dementia part of promoting healthy lifestyle
• Independent partnership of private, public & voluntary sector organisations with aim to improving lives
• Partnership in ideas, support & progress, to ensure Enfield becomes dementia-friendly community
• Some of most active partners have been specific community groups promoting issues of dementia
• LBE/CCG invests £3m/year in grants to voluntary sector – 70+ organisations work with older people
• LBE developed collaborative VCS Framework
Connecting Communities Project

‘In the last months of his life, my dad had Vascular Dementia…in my community people were saying my dad had gone crazy, and that the disease was payback for something bad in his life’

- Enfield fortunate to have access to Alzheimer’s Society Connecting Communities pilot
- Promote dementia-awareness in communities with potential barriers in knowledge or access to services
- Project worked with 15-20 community organisations, with 550 attendees at workshops
- Particularly amongst SE Asian, Turkish, but also African & Caribbean and Greek groups
- Increased referrals to memory clinic from groups
Plans & Challenges

• Enfield partnership submitted bid for Healthy Ageing Programme for Older People & Social Isolation
• Will develop voluntary sector hub in primary care alongside statutory sector integrated care solutions
• Will be focus on improving post-diagnosis support
• Collaboration across diversity groups and will also reach out to those disabled, elderly & frail and carers
• Invest in support for carers later in pathway
• Collaborating with residential/nursing care providers
• Need imaginative ways to reach specific groups, LGBT community and men in some ethnic groups
• Expected to invest from Better Care Fund