Equality and health inequality issues and dementia

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‘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’
‘Dementia does not discriminate’

- Dementia affects all of us
- But we experience dementia as individuals:
  - Our age, gender and so on
  - Our life experiences
  - Our personality
- Challenge is to develop support that recognises BOTH these aspects

Dementia does not discriminate

The experiences of black, Asian and minority ethnic communities

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Equality Act 2010: A framework for looking at inequalities in dementia

- 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
Age (1)

- Risk of dementia increases with age
- Social inequalities in health widen and converge at different ages
- Gerontologists suggest health in old age is affected by inequalities across life course
But increasing numbers diagnosed before age of 65

- 42,325 is latest estimate for UK, includes people in 30s/40s
- Difficulties getting a diagnosis
- Increased stigma
- May face different issues (e.g. employment, young children)

http://www.youngdementiauk.org
Disability

- Office for National Statistics data shows variations by age, region, ethnicity, income

- Only 17% of people have ‘just’ dementia (Banerjee, undated)

- Extent of ‘diagnostic overshadowing’?
Dementia and learning disability

- Poor estimates of number of people with a learning disability, especially those aged 18 and over
  - In 2010, estimated 58,897 of 191,469 learning disabled adults aged 50+ (Emerson et al, 2010)

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

Joseph Rowntree Foundation & University of Edinburgh DVD
Gender

- More women than men have dementia
  - Some say mainly attributable to different life expectancy
  - Others say different prevalence rates (e.g. Roberts et al, 2012)
- We need to include a gender dimension in service evaluations (Bamford, 2011)
Sexual identity (1)

- Only beginning to be addressed in dementia research
  - Experiences of discrimination as carers (Price, 2008)
- Stonewall research with LGB people aged 55 and over (Guasp, 2011)
  - 41 per cent of older LGB people live alone compared to 28 per cent of heterosexual people
Sexual identity (2)

- Stonewall research also found that:
  - Gay and bisexual men aged 55 and over much more likely to be single (40% compared to 15% of heterosexual men)
  - Differences in relationship status between lesbian and bisexual women not statistically significant (30% compared to 26%)
  - Previous experiences of discrimination were a major barrier to using health and care services for LGB men and women

- Uhrig (2013) found that:
  - Higher proportions of older LGB people are living in poverty
  - Less than one per cent of those aged 65+ self-identify as gay or lesbian compared with 4% of those than those aged 16-24

- US research shows effects of sexual identity on social support mixed
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

- Gender and sexual identity are not the same
- ‘Binary’ gender distinctions do not reflect many people’s perceptions of themselves
  - We don’t routinely ask whether people self identify as transgender/intersex/or other identity
  - We know there is a population of older people who transitioned in 1970s
  - We know there is a population of people who identify as transgender or who cross dress without having surgery or taking hormone treatments
Marginalised

- Differing views as to advantages/disadvantages of grouping with LGBTQ people
- Research with transgender people suggests many people have had experience of discrimination which may influence ‘help seeking’ behaviour
- Research with international sample of transgender adults aged 60 and over (McFadden et al, undated) found they were very concerned about developing dementia
  - Concerned about intimate care
  - Concerned they will be treated in ways not congruent with gender identity
Projected increase in numbers of BAME people with dementia (APPG, 2013)
What we currently know

- Emerging picture of different risk factors for different types of dementia
- 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 in some communities (LaFontaine, 2007)
- Carers may experience particular difficulties (Bowes & Wilkinson, 2003)
Religion

- In some instances may be more appropriate to look at ethno-religious groupings when examining social inequalities in health (Hills et al, 2010)
  - But generally reported just in terms of ethnicity
- Limited research looking at way religious beliefs influence help-seeking behaviour
- Emerging evidence on how religious beliefs influence ideas about dementia (Regan et al, 2012, Regan, 2013)
- Risks of stereotyping
  - In 2001 Census, Chinese people were the ethnic group most likely to say they had no religious affiliation
Religion and ethnicity (2010 census)
Socio-economic status and intersectionality

- 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?
- Research often presented in terms of one characteristic but better to think of intersecting or overlapping characteristics
Conclusions

- Everyone has the right to the same opportunities to plan what support they want and have access to treatments that may delay progression of dementia.
- Social inequalities become increasingly important as we learn more about potential for risk-reduction in dementia.
- We have multiple identities so important not to look at just one aspect.
- Considering these factors is an essential step in delivering more person-centred dementia care.
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