Understanding Ethnicity and Cultural Diversity in Dementia Care: A Person-centred Approach

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Overview

• Who am I talking about?
• What do we know about them already?
• My doctoral research
• What’s happening now?
Ethnicity

• Multi-dimensional, usually encompasses one or more of the following:
  • ‘shared origins or social background; shared culture and traditions that are distinctive, and maintained between generations, and lead to a sense of identity in groups; and a common language or religious tradition’ Gill et al (2007: 228).
Culture

• Multi-dimensional: Encompasses several components including ethnicity, religion, gender, socio-economic class, sexual orientation...

• ‘The term culture could be defined as the set of beliefs, knowledge, art, morals, laws, customs, and any other habits or dispositions acquired by a human being as a member of a society’ (Olarte and Guillen 2001: 47).

• Determines how people view and make sense of the world.
Culture cont...

- Cultural factors influence the ways in which health and illness are perceived – our norms, beliefs and traditions around illness/health, care-giving, dying, death and bereavement are shaped by our cultural backgrounds.

- Black and Minority Ethnic communities (BME)
Minority ethnic communities

• ‘A minority is a sociological group that does not make up a politically dominant voting majority of the total population of a given society’ (Wikipedia 2011).
• Not a numerical minority – different from dominant groups
• Marginalised communities
• Hidden communities
• Migrant communities

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Dementia in the UK

• There are currently 750,000 people with dementia
• There are over 16,000 younger people with dementia
• There are over 11,500 people with dementia from BME groups.
• There will be over a million people with dementia by 2021
Dementia in BME communities: Research

Moriarty *et al* (2011):

- Research – scant & piecemeal: small number of local studies
- Limited research on the experience of dementia between the different ethnic groups
- Research has focused on carers of people with dementia
- **Key findings**
Dementia in BME communities: 
Findings

Moriarty et al (2011); Jutlla & Moreland (2007); Seabrook and Milne (2004):

• Greater chance of developing dementia
• Lower levels of knowledge and awareness about dementia
• No word for ‘dementia’ in any of the South Asian languages
• Stigma of mental health
• Hidden problem
• Low dementia diagnosis
• Present themselves in crisis situations: need for early intervention

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Dementia in BME communities: Findings cont...

• Lack of knowledge & access to services
• Lack of culturally appropriate services
• Language barriers
• Reluctance to ask for, and accept, formal support
• Familial roles and a duty to care
• Need to portray an image of well being to those outside of the family
• Assumptions about community support – ‘They look after their own don’t they?’ (DoH 1998)
Research

Forefront of policy and practice

In depth understanding about their experiences of living with dementia

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Dementia in minority ethnic communities

Location

Personal histories

Experiences of migration
Ireland (2006 census)

- Ethnic groups
  - Irish 87.4%
  - Other white 7.5%
  - Asian 1.3%
  - black 1.1%
  - mixed 1.1%
  - unspecified 1.6%

- Religion
  - Roman Catholic 86.8%
  - Church of Ireland 3%
  - Presbyterian 0.5%
  - Methodist 0.25%
  - Muslim 1%
  - Jewish 0.1%
  - Other 8.35%
## Worcester (2001 Census)

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<td>Jewish</td>
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## Wolverhampton (2001 Census)

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Caring for a person with dementia: a qualitative study of the experiences of the Sikh community in Wolverhampton, UK.
The participants

• 12 carers of people with dementia:
  – 9 women, 3 men
  – 5 spousal carers, 7 intergenerational carers
  – 5 from rural Punjab, 2 from East Africa, 2 British educated, 3 British born
Narrative interviews

• Interview 1: From the time that the participant first noticed symptoms of dementia until present
• Interview 2: Experiences prior to migration and reasons for migration
  – Post migration experiences up until the time when they first began to notice symptoms of dementia in the person that they are caring for
  – *British educated/born Sikhs*: their own personal history including the migration history of their family

• 1-3 hours each
• Field notes
Narrative & Biography

• In-depth understanding of experiences across the life course, including those of migration

• Never been applied to carers of people with dementia

• Sikhs: Marginalised communities
• Carers: often isolated
  – Gives voice – things that are important to them
Narrative & Biography cont...

• Gives meaning:
  ‘they foster an unfolding of the self and help us to centre and integrate ourselves by gaining a clearer understanding of our experiences, our feelings about them, and their meaning for us. The stories we tell of our lives bring order to our experiences and help us view our lives both subjectively and objectively at the same time while assisting us in forming our identities’ (Atkinson 2002: 122).

• Reflexivity
Positioning Theory

• A blueprint for understanding people’s multiple affiliations and identities revealed through their use of language

• No clear single definition, though many theorists refer to the work of Davies and Harre (1990: 48), who refer to positioning as:

‘the discursive process whereby selves are located in conversations as observably and subjectively coherent participants in jointly produced story lines. There can be interactive positioning in which what one person says positions another. And there can be reflexive positioning in which one positions oneself.’
Positioning Theory cont...

- The participants various positions & my research questions:
  - Migrants
  - Role within the family
  - Carers of a person with dementia
Positioning Theory: The Sikh Community

• Use of language:
  – Experiences of migration: the Sikh community is ‘us’ and ‘our’ people
  – Experiences of caring: the Sikh community is ‘them’ and ‘those’ people
Findings

• Analysis: Constructivist Grounded Theory

• The ways in which they manage and negotiate the responsibilities associated with caring for a person with dementia are dependent upon the positions they uphold and the contexts in which these are happening
Social context

• Immediate and/or extended family

• The Sikh Community in Wolverhampton

• National: Ethnic Communities

• International: migration and historical context
The system

• Local organisations and services

• National policy and practice for ethnic communities

• International: politics and the economy
A process of (re)positioning

• (Re)positioning between the CARER ROLE and their RELATIONAL ROLE to the cared-for person within and across these various contexts
4 inter-related areas of existence

- Social Context
- The System
- Carer Role
- Relational Role
- Carer Role
- Relational Role
- Social Context
- The System
As their relational role to the cared-for person within their social contexts

• Participants’ quests for assistance and support with caring were not just within the context of the family, but also the wider Sikh community of which they are a part of.
As their relational role to the cared-for person within their social contexts cont...

- Lack of informal support from within the Sikh community in Wolverhampton
- No concept of the caring role
- Pressure and expectations to conform to the duties associated with their relational role to the cared-for person
- Wider discourses: Cultural norms about gendered roles and positions in the family
The case for Ram Piari
‘With us as being Indians or Asians... it’s like the besthi (shame) if you turn around and say that I can’t cope with looking after this person anymore... if we turned around and it got to the stage where dad needed feeding... washing...medication and bedpans... and whatever else... I don’t think my husband could do it and to tell you the truth... I don’t know if I can do it. So it would mean putting him in a home...And it would be the besthi (shame) of that. People would actually point their finger and say look, look what so and so’s son did... threw him out the house... and I think that is a community attitude... whereas ... I’m not saying that it doesn’t happen in the White population... I’m sure things like that would happen... but... people are more objective ... they would turn around and say well actually yeah perhaps it was too much responsibility for that one son or daughter-in-law to look after them and probably he’s getting better treatment now than he would have been at home... but our community just really pressurises us... and it does make me angry you know...
Ram Piari cont...

• ....[5 second pause] but then, stepping aside from what the (Sikh) community has to say about it, when I think about having to put dad into a home... And that time may well come... I think well... How will he cope in a home when they are mainly set up for White people? His needs are different... The foods he eats, the way he does things.. His language and all that. So I guess it’s a no win situation really’ (Ram Piari).
• When informed of her financial entitlements, she stated: ‘I've never asked because they'll start saying... she's taking money for her mom. It's very expensive, they (Asians) don't realise... it's hard to get by.’

• The stigma that would be attached to her therefore resulted in her initial refusal of financial entitlements
‘I really struggled at the beginning... Mainly because I wouldn’t send dad to day care. I was scared of what the (Sikh) community would say about me for sending him... That I wasn’t a good daughter... And that I couldn’t look after him properly. But the CPN encouraged me to do it and although it really helps me because I work as well, I still feel that they are pointing fingers at me. It’s horrible really... I feel like an outcast.’
As their relational role to the cared-for person within their social contexts

cont...

• Pressure and expectations to conform
• Ambivalent towards the (Sikh) community
• Isolation
• Depression

• A need for informal support (emotional and practical)
As their relational role to the cared-for person within the system

• The extent to which they accept formal support is determined by:
  – Informal support
  – Being defined as a carer
'The GPs nurse... she’s quite good as well... although there’s the ethical thing of confidentiality... she appreciates the fact that I do a lot of the caring and the medication... so she does tend to share SOME stuff with me... not the very confidential stuff ... but she will say look... this is what I think may be happening in a round about way so you get the gist of it...and I really have to be thankful of that because sometimes I’m thinking well why’s he feeling light headed? But then she explains well you know... it’s because of this... he’s on this medication because of this. So in that sense... the actual dementia caring thing... we’ve had nothing really because the main carer was classified as my mother-in-law... she doesn’t give two hoots, plus she can’t speak English and she’s not gonna travel anywhere. So it’s only in the last four months that my husband has become the registered carer... but it’s still me who actually asks for the information.'
As their relational role to the cared-for person within the system cont...

- Difficulties for those who are caring and not registered
- Lack of joint family support
- Carers as resources
A carer within the system

• Experiences of formal support
• Cultural competency issues
  – Religious requirements associated with being a baptised Sikh
  – Gender & ethnicity

  – ‘Having Asian staff is not the answer’ (Darshan Kaur).
‘Her [mother’s] benefits weren’t covering it so everybody, all the sisters were putting in their little bit so that she can stay in this fantastic home... and there were actually...I think about four, maybe even five carers or nurses whatever... staff... that were Punjabi. But, that was another thing because if...when mom knew this is a lady called... I don’t know... Usha or Parveen or something that she knows that’s not Sikh, that’s Hindu...or in the conversation it would come out... then that would be another thing that she didn’t sort of... it’s almost like...if it’s completely ‘Goreh’ [White people] you know it’s one thing, but it’s... it does play on their mind doesn’t it? you know whether they’re Jat... so you know, you can say that you don’t have those sort of problems... but it’s just in their system really isn’t it? She’s not horrible about it, she wouldn’t ... I wouldn’t think she’d...well I’ve never heard her say anything, like insult anybody but ... it’s still there...so having Asian staff is not the answer.’
A carer within the system cont...

- Diversity of Asian communities
- Diversity within the Sikh Community
- A person-centred approach
Professor Tom Kitwood

- Person centred approaches to care
- The enriched model of dementia
- Supporting personhood
Underpinning philosophy

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
Person centred care fit for VIPS

V = Values people
I = Individuals needs
P = Perspective of service user
S = Supportive social psychology
Starting point

When you’ve met one person with dementia.....
You’ve met one person with dementia!

Emphasised by my doctoral research
A person-centred approach

• Understanding cultural norms and discourses help us to understand where people are coming from... Helps us to understand *why*

• People’s interpretations of those norms are dependent upon their own life experiences

• One size does not fit all
The most important question...

• What’s being done about it?
Association for Dementia Studies

- Education & Training across Health and Social Care - Cultural Competencies: A person-centred approach
- Higher education: optional module
- Teaching resources: a short film
- The Dementia Ambassador’s Project
- Further research:
  - Spirituality and Sikhs study
  - Conceptual framework as a methodological tool
- Creative therapies
Association for Dementia Studies

• A substantial contribution to building evidence-based practical ways of working with people with dementia and their families that enables them to live well – through education, research and scholarship.

• Care fit for VIPS: http://www.carefitforvips.co.uk/

• Stand By Me
  • The ADS website: http://ihsc.worc.ac.uk/dementia/
Any questions?

Contact details:
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• **References**