Dementia, Relationships and Care giving in minority ethnic communities: Experiences of Greek Cypriot and African Caribbean Partners
Background (1)

• This session will describe a study completed as part of a PhD programme at Northumbria University
• Supervision team – Professor C. Clarke and Dr C. Gibb
• The study was conducted in an ethnically diverse borough in North London
• Initially inspired by Admiral Nurse role in supporting carers of people with dementia
Background (2)

• Growing cultural diversity among UK older population (Lievesley, 2010)
• Evidence that ethnic background is significant in terms of the experience of dementia within families (Hinton et al., 2005; Moriarty et al., 2011)
• Little evidence on the impact of dementia within the UK African Caribbean population
• No studies on the experiences of Greek Cypriots in the UK
Study Aims

• To add to the small but growing knowledge base around dementia and ethnicity, through an in-depth exploration of the experiences of Greek Cypriot and African Caribbean partners of people with dementia
Method – Constructivist Grounded Theory

Phase One
- Focus Group/One to one interviews
- 6 African Caribbean and 10 Greek Cypriot people

Phase Two
- Up to four in depth interviews with partners of people with an established dementia diagnosis
- 6 African Caribbean and 7 Greek Cypriot partners (plus three children)
Main Phase

• In depth interviews with partners of people with an established dementia diagnosis, some via interpreter
• Recruited via Mental Health Services for Older People
• Up to four interviews with each participant
• Themed but conversational – guided by participants
• Recorded and later transcribed
• Analysis concurrent
Results (1)

Partners of people with dementia were engaged in an ongoing process of ‘redefining relationships’.

Underpinning processes were:

- Recognising
- Reacting
- Adjusting
- Shielding processes influenced the impact of dementia-associated changes of relationships.
Results (2)

- All partners recounted a significant time lag between noticing changes and receiving a diagnosis.
- There was a tendency to ‘normalise’ changes and in many cases view them as part of ‘normal ageing’.
- Cypriots more proactive in seeking diagnosis than African Caribbeans.
- Responses to the diagnosis or changes varied but were not associated directly with ethnicity.
Results (3)

- Cypriot partners tended to emphasise family relationships over and above the couple relationship.
- African Caribbean partners emphasised a view of themselves primarily as an individual or as part of a couple.
Results (4)

• African Caribbean partners were more likely to be receiving formal care services than Greek Cypriot partners.
• This was not related to degree of dementia or presence of perceived challenging behaviours.
• Greek Cypriot partners expressed a preference for and expectation of family care. For some this was not new, but an extension of pre-existing arrangements.
• African Caribbean partners appeared to be influenced by a concern not to ‘burden’ children and/or to be independent.
‘I don’t have any expectations that you would be caring for me when I’m older, I don’t. Because I think you have a responsibility towards your children there who need you. So that if they find it strange sometimes I said if I’m here and I get a phone call from you it’s lovely, but I don’t expect it. If I get it it’s wonderful, and I’m not just saying that. But say I don't love them - I love them very much and I would do anything and everything for them, but I’m not expecting them to be my carers. No I don’t.’ (African Caribbean woman)
• ‘If I can’t look after her then, unless we get somebody in the house to come and look after her. If I can afford to do that then I keep her home. But if I’m not then we have to. But still it’s not going to happen because my daughter is gonna come. She’s gonna look after her. Definitely she’s not going to the Home.’ (Greek Cypriot man)
Conclusions

• Culture and ethnic background appear to have some significance in relation to how people experience having a partner with dementia but are not able, on their own, to explain the variety and range of ways in which people deal with their situations.

• Awareness of cultural background and knowledge of prevailing cultural attitudes are only starting points for the practitioner.

• An appreciation of the uniqueness of the individual – through learning about their attitudes, relationships, resources and experiences, and personal life stories, is also important.
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