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Improving dementia care for African Caribbean patients and their families

Dementia Across Cultures Conference

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Outline

- Context
- Outline study
- Findings
- Discussion
  - Suggestions for future research

Context

- African Caribbeans significantly higher risk than White British peers (OR 3.07, 95% CI, 1.28-7.32)
- Higher rates vascular dementia
- Younger (almost 10 years)
- Later access with more advanced symptoms

(Adelman et al., Br Journal of Psychiatry, 2011)

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Context

- Manchester >30% African Caribbeans 60+
- ‘High risk’ due to risk factors such as:
  - Prevalence vascular disease
- Low uptake specialist services
- Manchester Supporting Health Programme (MSHP) dementia project – target ‘high risk’ groups

Aims & Objectives

Aim:

Pilot methodologies for gaining insight into African Caribbeans' low uptake of specialist dementia services

Objectives:

1. Explore trans-generational perspectives on ageing, dementia & dementia care among African Caribbean families
2. Test feasibility of undertaking qualitative research in 'hard-to-reach' BME group

Methods

Recruitment:

Local Media, posters and flyers in: ‘Black Majority Churches’, voluntary sector, community groups

Inclusion Criteria:

Family member with history of dementia

African Caribbean origin

18 or older

Able to give informed consent

English speaking

Methods

- Qualitative study
- Individual/group interviews
- ‘Topic Guide’ from literature and ‘Faith & Dementia Conference’
- Data Analysis
  - Thematic analysis
  - NVivo to support data management

Findings

Participants

- N=20 (17 interviews) – 1 couple, 1 family
- Female (n=15), male (n=5)
- Age range: 18 – 74; (14/20; 40+)
- ‘1st generation’ (n=7); ‘2nd generation’ (n=11); ‘3rd generation’ (n=2)
- 13/20 participants’ parents had dementia
- Others: aunt, grandparents, ‘in-laws’, sibling, spouse

Findings

Key Themes

- Beliefs about dementia
- Dementia care
  - Getting help
  - Experiences
  - Cultural issues
- Ideal model of care

Findings

Beliefs about causes of dementia

1. Unresolved inner conflict

- *‘ Because she’s not a woman who really speaks her mind or shares her thoughts. So it makes me wonder sometimes whether this is the problem or that’s what started it.’*

Participant 3

- *‘I think dementia stems…from unfulfilled dreams.’*

Participant 7

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Findings

Beliefs about causes of dementia

2. Biopsychosocial?

- *'…and then that memory box, it's locked ... it's like a confusion …a puzzle ...and if you don't get that piece in that correct place you never make it.'*

Participant 11

- *'Within the Jamaican culture there is an understanding that they may have been bewitched…'*

Participant 4

Findings

Getting help

- *‘We will battle on to the very end, kind of thing, and only then [in crisis] we tend to go for help.’*

Participant 8

- *‘You don’t know where to start…It’s all so new, you don’t know what you need ... really difficult because I went to my GP, I went to social services, and they argued between themselves as to who, where Mum should go.’*

Participant 5

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Findings

Getting help

- *'…and she [GP] said… "I'll write your mum up for these tablets" of course that got me a bit angry because the first thing she thought was putting my mum on some psychotic drug or some drug. And I said to her, "No. I do not want my mum putting on tablets. I want you to find out what the cause is first* ***before*** *(stresses) you put my mum on some tablets"… so she said "okay…I'll refer you to one of the hospitals."'*

Participant 12

Findings

Experiences

- One carer returned to a care home after two days to find her father still wearing the same clothes as when he arrived, with his suitcase including all his toiletries, untouched beside him.
- Her father dehydrated with untouched drink by his bed: *‘I thought, “we told them that he can’t pick up anything and drink it himself, so why have they done that?”’*

Participant 6

Findings

Experiences

- Needing to educate professional carers about dementia and close personal care – especially skin and hair
- *‘every new one [carer] that comes, we have to start over...show them how to cream his [father] skin, which products to use...by the time you’ve trained them up, they move on and you have to start all over’*

Participant 9

Findings

Cultural issues – importance of the familiar

- *‘They might not want to eat ackee and salt fish every day, it would be nice for them to be offered African Caribbean food at least sometimes’*

Participant 15

- *‘Mum’s never had a huge Jamaican accent, but as her dementia has got worse it seems her Jamaican accent is coming back more and more and more. And just being around people who actually understand what she’s saying seems to make a difference.’*

Participant 1

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Findings

Cultural issues and misunderstandings

- *'When we're combing our hair we tend to leave the comb in the back of our head, in the hair. And the people misunderstood that and took it that he needed more medication…'*

Participant 16

- *'it is assumed they are defaulted back to traditional linguistic trends from their home country. So the medical services just assume they're using Creole English or maybe African pigeon English…so they don't see it as a problem until it gets to a point where it's significantly presented.'*

Participant 13

Findings

Ideal model of care

- *'It would be nice if they (had) care homes for Afro Caribbeans… the only thing that's good about that, they have all people from their culture will be there. And they can maybe reminisce…about their old time in the West Indies (and…in the care home that she is in, she wouldn't get that).'*

Participant 9

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Findings

Ideal model of care

- *'If you get to know the family, it is so important because people can be from next door and they are not brought up the same way. And therefore their needs are completely different…But by knowing the family or where these people come from…what they were when they were in their right minds…then you are able to sort of break down things and supply their needs.'*

Participant 17

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Findings

More partnership working

- *‘And the community…need to be educated regarding dementia . And I think one of the best ways…to reach out…is to use the organisations that exist, like the church... the church does play an important part in our community and I believe that would be the first port of call.’*

Participant 3

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Summary

- Confirmed likelihood later access to services
  - Duty and responsibility of care
    - ‘Keep going to the end’
  - Beliefs and help-seeking
    - Not medical problem
  - Isolation
    - People with Dementia
    - Carers
  - Access barriers e.g. GP knowledge, ability
    - Need for advocacy – family, community groups

Summary

- Poor experience of care
    - Lack of stimulation
    - Inability to provide culturally-appropriate close personal care – skin, hair, food
- Lack of education and training
    - Health professionals (trained and untrained)
    - Carers and families – symptoms, interventions, support
    - Wider community – managing risks e.g. vascular
- Need for closer partnership working
    - Architectural design e.g. ‘safe spaces to wander’
    - Statutory services, voluntary agencies, families and community organisations

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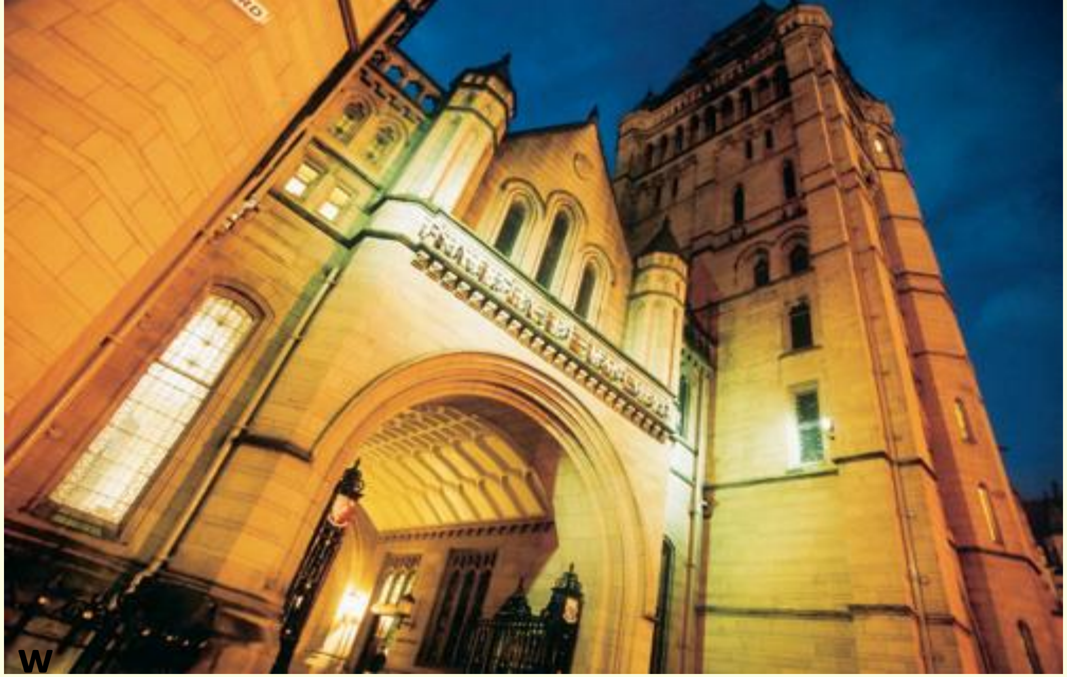
Discussion

- What's your experience of working with African Caribbean PWD and their families?
- What do you think should/could be done to improve dementia care?
- What are your views on 'culturally-sensitive' services e.g. necessity, feasibility?
- In which topic areas, do you think further research is needed?



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