

Preparation among caregivers of people with dementia: *findings from the Caregiving HOPE study*

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The UK context

- Approximately 850,000 people living with dementia in the UK
- 670,000 carers of people with dementia
- Carers save the NHS an estimated £11 billion per year
- Aging population means family carers will be relied upon more in the future
- Negative impact of care role is well-documented



Healthcare professionals often assume that carers are **willing** and **prepared** to provide care...



Obligated to provide care...but willing and prepared?



Willing to provide care...but prepared?





PREPAREDNESS

*“Perceived readiness for the multiple domains of
the carer role”*

(Fujinami et al, 2014)



The current study

How obligated, willing and **prepared** do family carers feel about dementia care?

Are there cultural differences between white British and British south Asian carers?



Our methods



185 South Asian carers
518 white British carers

In-depth interviews with 11
south Asian carers and 10
carers white British carers

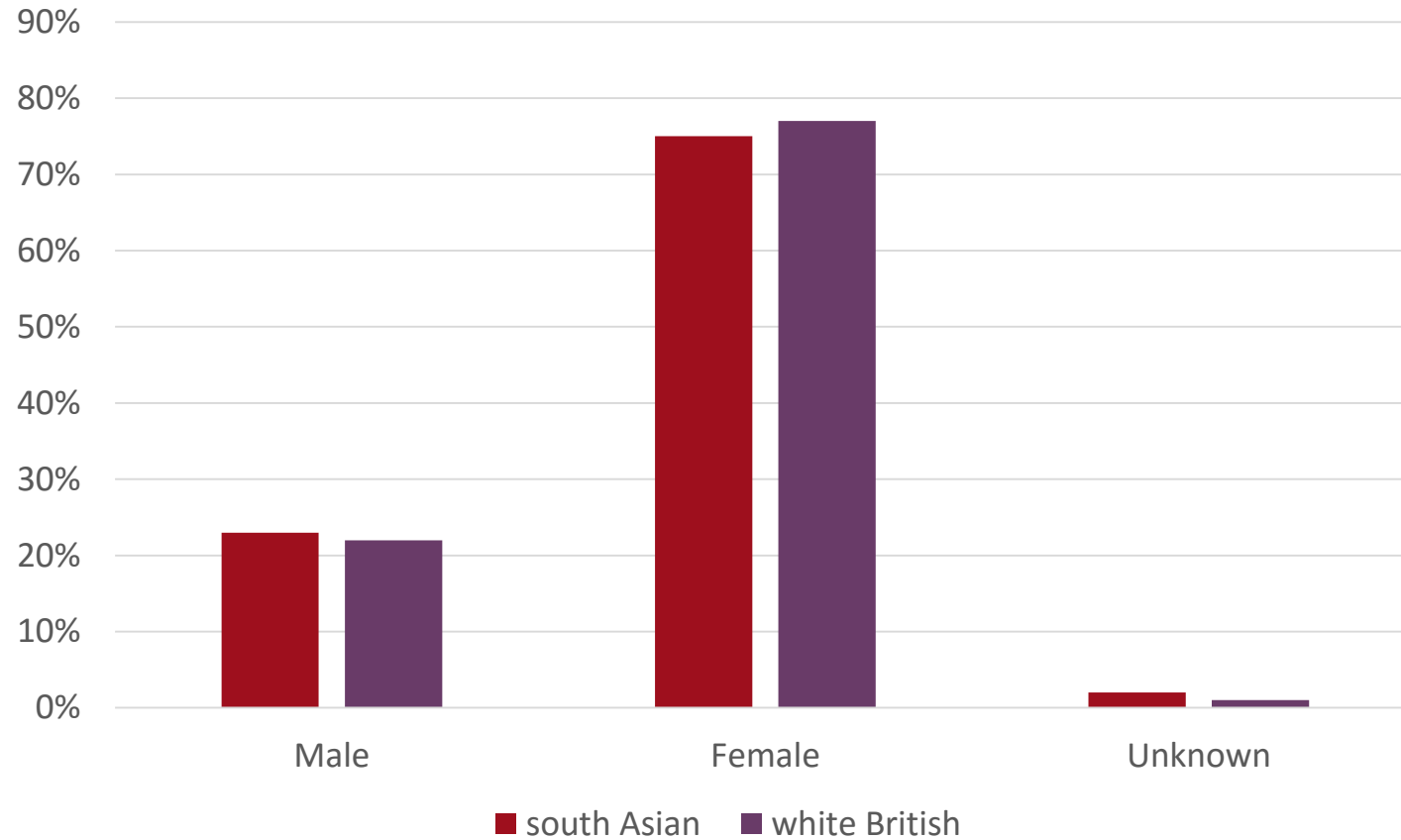


The results: Questionnaire study





Gender





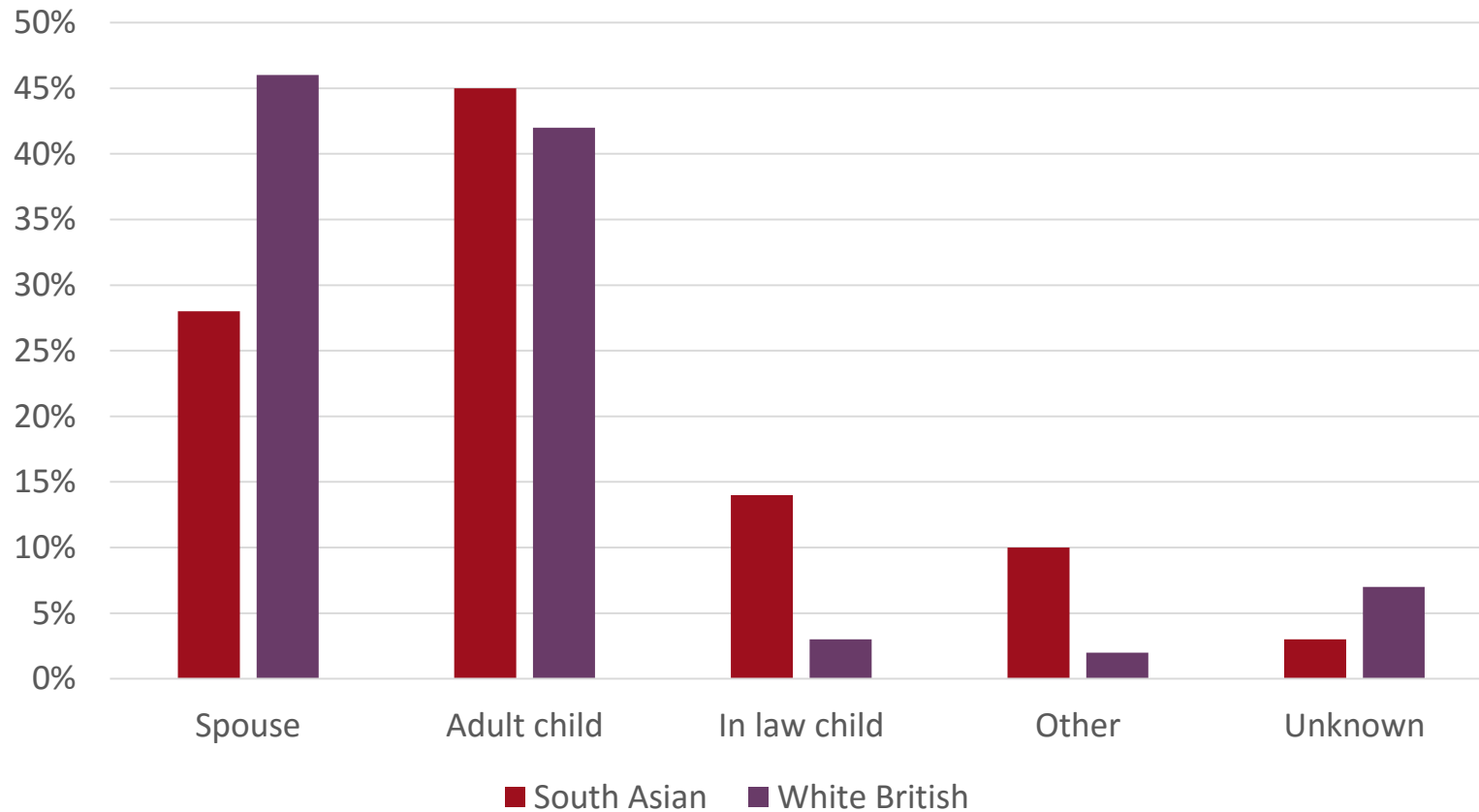
Age

| Ethnicity | Youngest carer | Oldest carer | Average age |
|---------------|----------------|--------------|-------------|
| White British | 20 years | 89 years | 64 years |
| South Asian | 18 years | 87 years | 50 years |



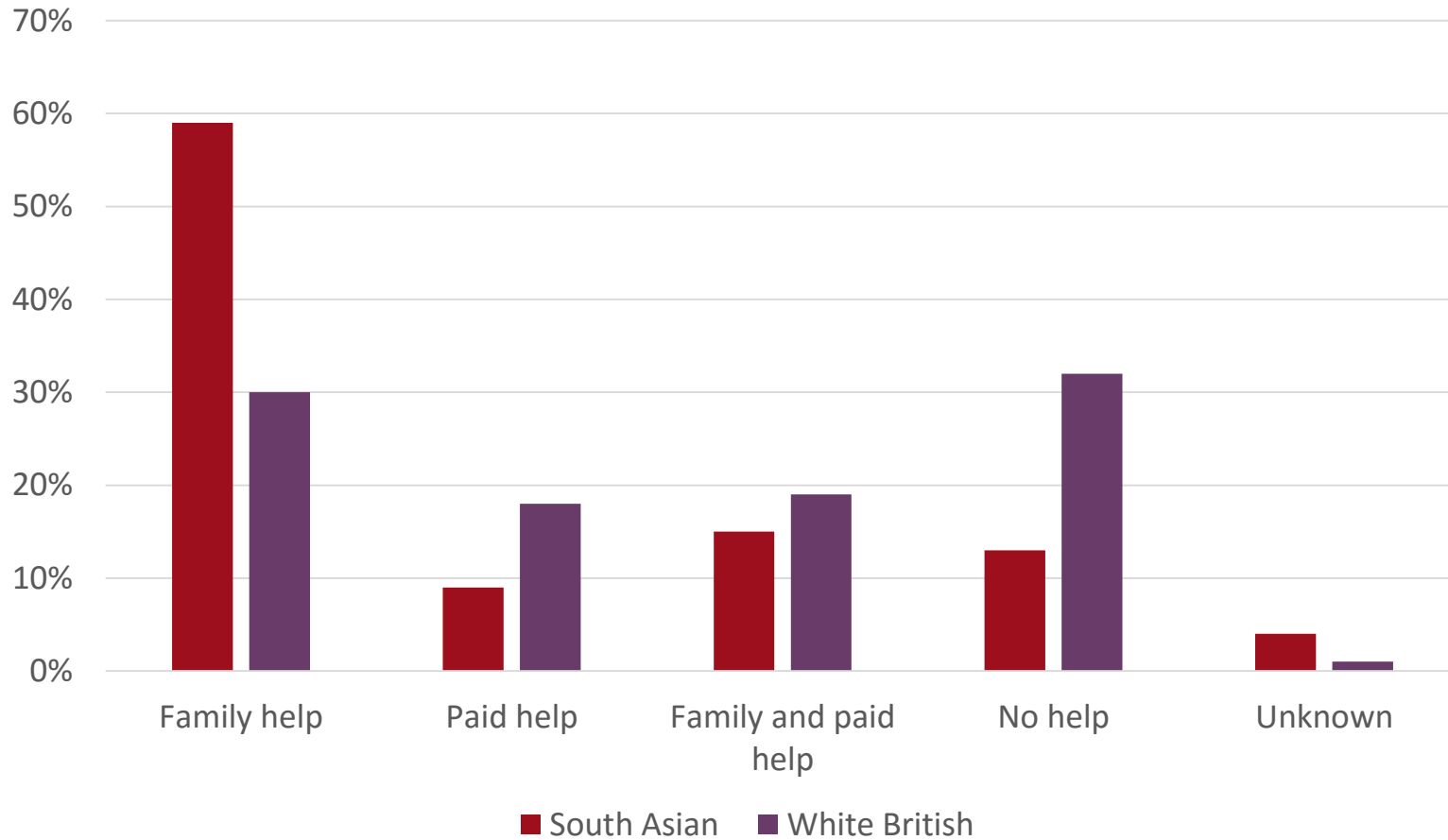


Relationship with person with dementia





Help with care





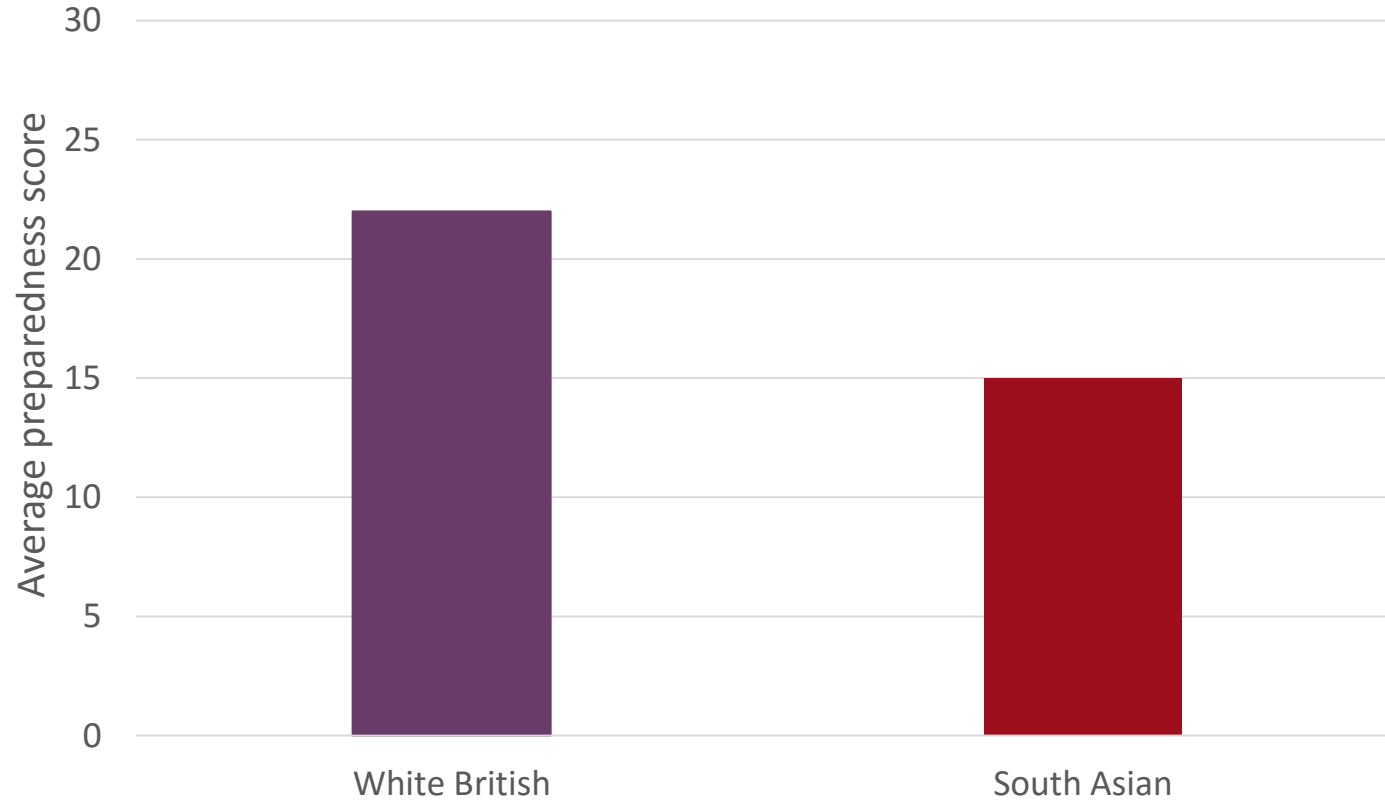
Hours and years caregiving

| Ethnicity | Average number of hours per week caregiving | Number of years in care role |
|---------------|---|------------------------------|
| White British | 78 hours | 5 years |
| South Asian | 85 hours | 7 years |



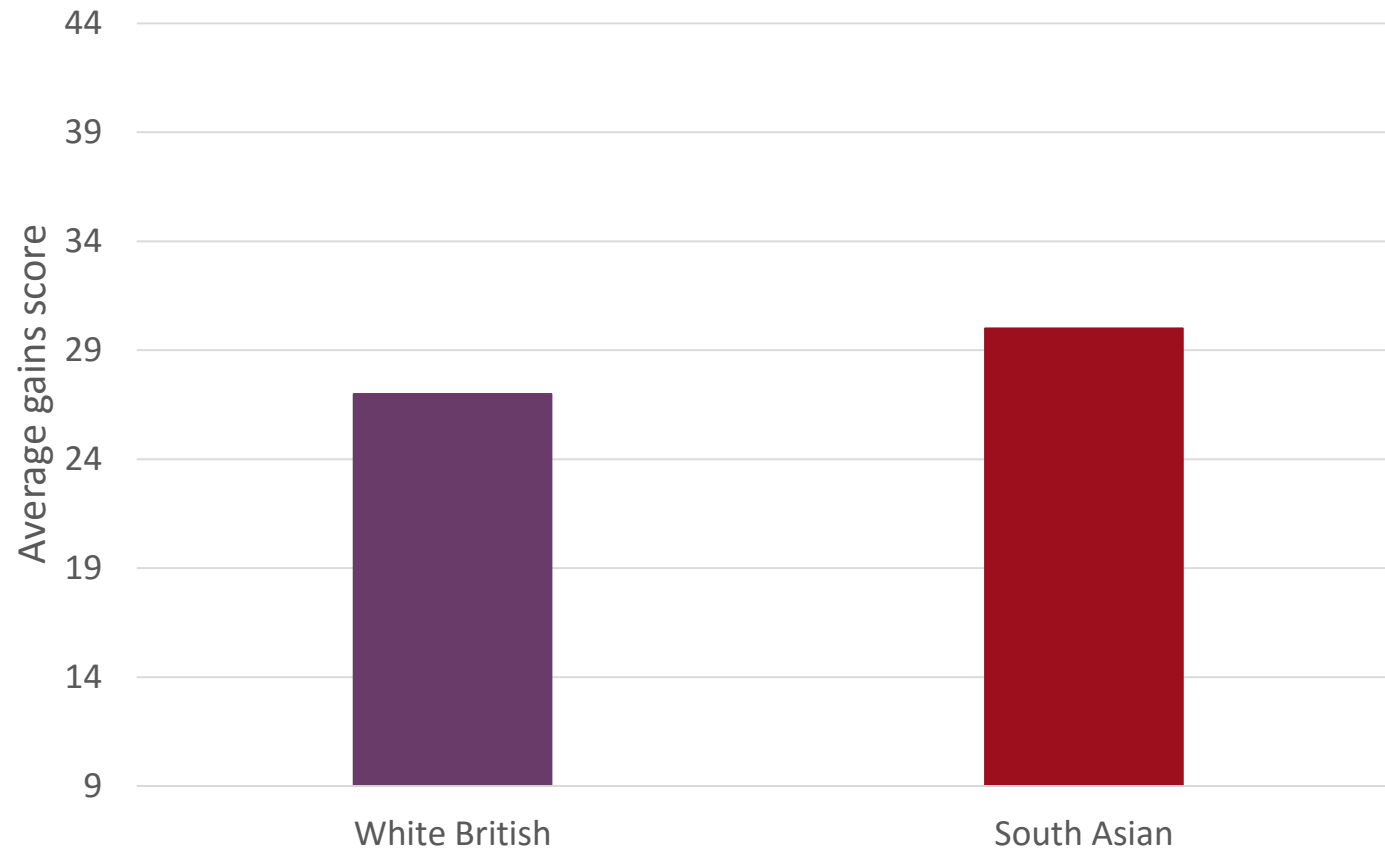


Preparedness (readiness)



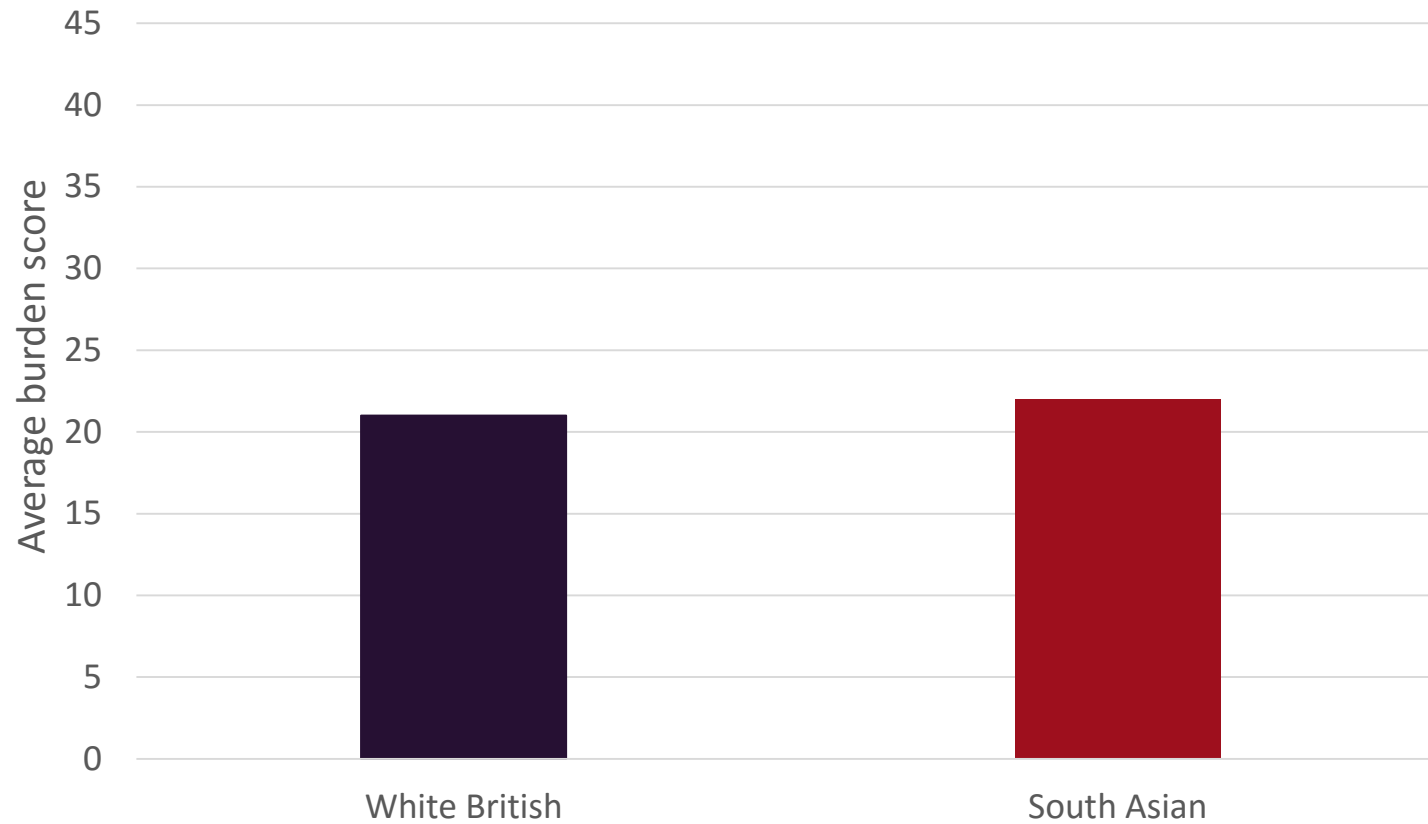


Carer gains



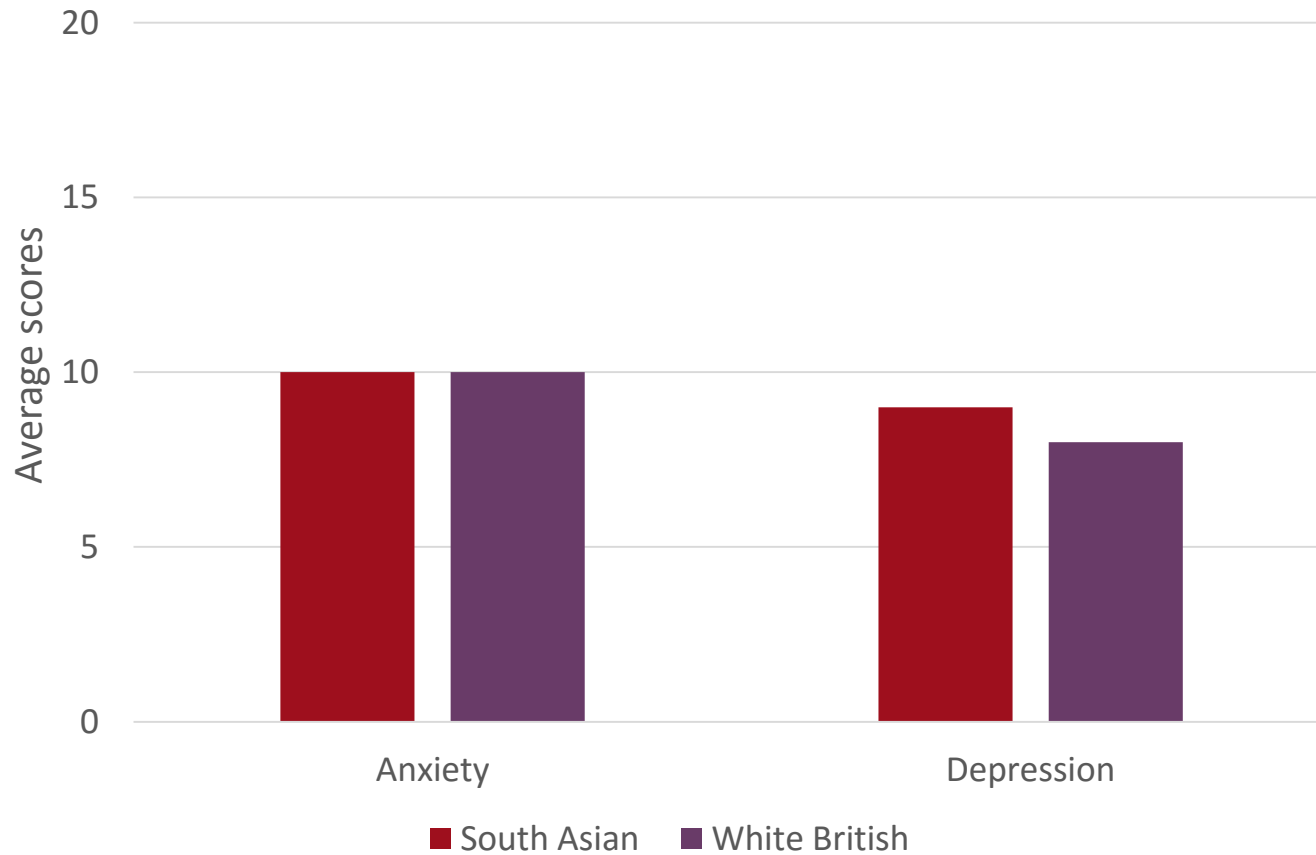


Carer burden





Carer anxiety and depression



| | South Asian | | | | White British | | | |
|----------------------------|-------------|---|---|---|---------------|---|---|---|
| | G | B | A | D | G | B | A | D |
| Familism (F) | | | | | + | - | | |
| Willingness-Emotional (WE) | + | - | - | - | + | | | |
| Willingness-Practical (WP) | + | - | | | | | | + |
| Willingness-Nursing (WN) | + | - | | | + | - | | + |
| PREPAREDNESS (P) | + | - | - | - | + | - | - | |

G = Gains
 B = Burden
 A = Anxiety
 D = Depression

+ = significant positive relationship
- = significant negative relationship





Next steps

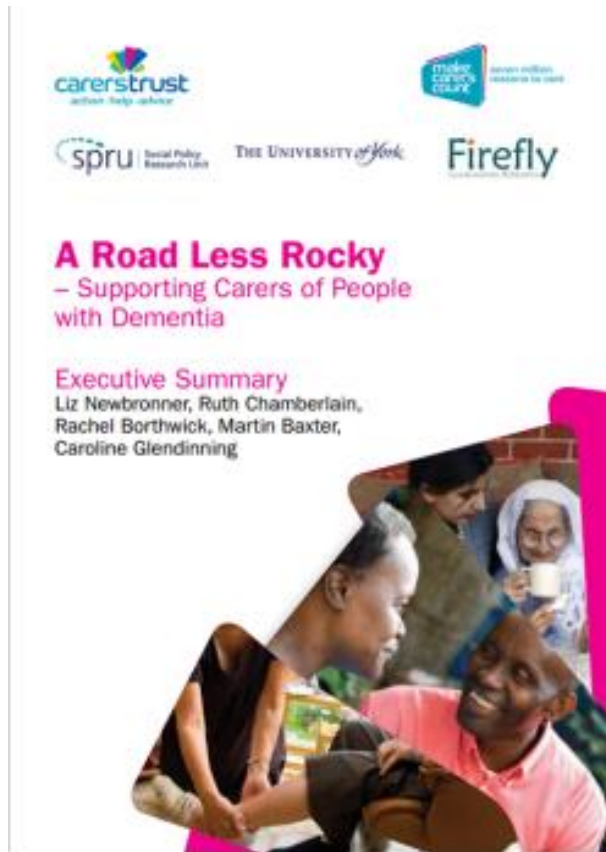
- We are currently exploring how obligations, willingness and preparedness change over time...
- ...and the impact this has on carer wellbeing



The results: Interview study



Transitions in dementia care



- When dementia is diagnosed
- When the carer takes on an active role
- When the capacity of the person with dementia declines
- When the carer needs a break
- When the person with dementia loses their mobility
- When the person with dementia has other health problems
- When the carer has to cope with behavioural problems
- When the carers own circumstances change
- When the person with dementia becomes incontinent
- When decisions about residential and end of life care have to be made

How carers prepared for caregiving

- Training courses (e.g. delivered by voluntary sector groups)
- Knowing the way round the health and social care systems
- Internet research
- Keeping a diary to organise daily thoughts and reduce tension
- Meeting and talking with friends
- Support groups and learning from other carers
- Taking care of own health and wellbeing

Preparedness for behavioural problems

White British carers

- Expected changes in the person with dementia
- Understood behavioural problems to be ‘unmet needs’ or triggered by environment
- Used a variety of psycho-social activities to reduce problems

British south Asian carers

- No understanding of dementia
- Behavioural problems were treated with medications
- Person with dementia blamed for ‘doing things on purpose’

Preparedness for decisions regarding residential care

White British carers

- Expectation that person with dementia will move into residential care.
- Knowledgeable and given choices with regards to types of residential care.
- Would like option to care at home.

British south Asian carers

- Not offered/told about residential care options.
- No knowledge of residential care processes.
- Cultural stigma attached to use of residential care from wider community.
- Would like culturally sensitive residential care.

Implications

- Production of Tips for carers book
- Development of time specific interventions focused on preparing carers
- Support carers to have realistic expectations of their role
- Influence the development of culturally sensitive services



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Thank you!

