

Obligation, Willingness and Preparedness to Care:

The Caregiving HOPE Study

Results Summary

2019

Contributors

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Background

- There are approximately 850,000 people living with dementia in the UK.
- Statistics suggest that in the future there will be a seven-fold increase in the number of people from south Asian (Pakistani, Indian and Bangladeshi) communities living with dementia compared to a two-fold increase in the white British population.
- There are 670,000 relatives (often referred to as carers) supporting a family member living with dementia.
- Carers supporting people with dementia save the NHS an estimated £11 billion per year.
- An increasingly aging population means more and more family carers will be relied upon in the future to provide care.
- There is a lot of research that shows that caregiving can be stressful for carers and have a negative impact on their quality of life.
- It is often assumed that family members are willing and able to provide care for relatives with dementia. This is particularly the case when considering south Asian families whereby members are considered culturally obligated to provide care at home.



This woman might feel culturally obligated to provide care to her father; but is she actually willing?



This woman might feel willing to provide care, but is she prepared for what that may involve?

What did we want to find out?

Based on past research and speaking to carers we decided to focus upon the following questions:

Study 1: Current Carers (Family member's already providing care/support)

1. How are cultural obligation, willingness to care, and preparedness associated and how do they change over time?
2. How do changes in the above influence changes in carer wellbeing?
3. What enabled current carers to feel more prepared and what advice would they give future carers?
4. How does the experience of south Asian families compare to white British families?

Study 2: Future Carers (Those who may become carers in the future due to having dementia risk factors within the family)

5. What are the attitudes and levels of knowledge with regards to dementia, and do they feel cultural obligated, prepared and willing to care?
6. Do attitudes towards dementia, cultural obligation and preparedness influence willingness to care?
7. What would enable this generation to feel more prepared for the carer role?



What we did

Study 1: Current carers

- We asked carers to complete a survey containing questions related to cultural obligation, willingness to care, preparedness, carer gains, burden, anxiety and depression.
- As we wanted to explore changes in people's feelings over time, we asked the carers to complete the same questionnaire 6 months later and then a final time 12 months after.
- We identified carers through 18 NHS organisations in England, carer groups and Join Dementia Research (an online database of volunteers).
- We also interviewed 21 carers, three times over 12 months to gain a more in-depth understanding of their experience. We gave them disposable cameras to take photos of things/situations that help them feel prepared and cope with their role.
- The photos and extracts from the interviews have been edited into a book: Living with dementia: The carers experience.

Study 2: Future carers

- We asked members of the general public to complete a one-off survey containing questions related to cultural obligation, willingness to care, preparedness, attitudes towards people living with dementia and plans for future caregiving.
- The survey was advertised in various places including but not limited to: Join Dementia Research, National and local newspapers, National and local radio stations, TV (BBC Look North), Social media, community centres, local shops and religious venues.
- We conducted 8 discussion groups with people to gain a more in-depth understanding of people's attitudes and feelings towards caring for a relative in the future. Over 50 people participated in these discussion groups.

What we found: Current carers

Who took part?

- A total of 723 carers completed the first questionnaire!
- Of which 187 were south Asian and 522 described themselves as white British.
- Approximately 77% of the carers were women and 22% were men.
- The average age of the carers was 60 years and the age ranged from 18 years to 89 years.
- South Asian carers were younger than white British carers and more likely to be adult children providing care for a parent.
- They were also more likely to be in employment and providing care for more than one person.

Differences and similarities between south Asian and white British carers.

- Not surprisingly South Asian carers felt more culturally obligated to provide care, HOWEVER
- White British carers were found to be more willing to provide emotional and nursing care.
- Both groups were equally willing to provide practical (cooking, cleaning) care.
- White British carers reported feeling more confident in their care roles and also more prepared.

Overall

- Thirty nine percent of the carers in this study had very high levels of anxiety and 40% of the group were found to have 'clinical levels' of anxiety.
- Approximately 23% of carers had 'clinical' levels of depression and 44% were 'borderline clinically depressed.'

Anxiety and Depression were measured using the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983).

Changes over time.



- A total of 328 carers completed all three questionnaires enabling us to explore changes in experience over time.
- Many people dropped out of the project because the person living with dementia either passed away or moved into residential care.
- The final group of carers were predominantly female (80%), white British (85%) with an average age of 61 years.
- Approximately 44% of the carers were adult children and 46% were spousal carers.
- Interestingly carers reported feeling less culturally obligated to provide care over time but their willingness to care did not change.
- Carer preparedness and confidence increased over time but so did carer burden.
- There were no changes in carer gains, anxiety or depression.

Relationship with carer wellbeing

- Feelings of cultural obligation to provide care were not associated with how willing carers were, or how prepared carers felt.
- Better preparedness was associated with feeling more willing to provide care.
- Preparedness was found to be associated with more carer gains and lower burden, lower anxiety and lower depression.
- This suggests, by helping carers feel more prepared for their role, we may be able to improve their wellbeing.

Interviews with carers

- Twenty-one carers (11 south Asian and 10 white British) participated in three interviews over one year.
- We included different types of carers in terms of relationship (grand-children, adult children, and spouses), gender, age (18-86 years) and also stage of caregiving (those who had just received a diagnosis to those who were no longer caregiving).
- The purpose of these interviews was to understand what enabled carers to feel prepared.
- The following major themes emerged from the data: having a positive and proactive approach to planning, being knowledgeable and having a good understanding of dementia, an understanding of the progression of care needs and access to support services.
- Carers discussed preparedness and coping with the following significant stages of care:
 - receiving a diagnosis,
 - when the person with dementia had multiple health issues (e.g. cancer and dementia),
 - managing complex behavioural needs,
 - moving the person into a nursing home,
 - when the carers own health deteriorated and
 - end of life care.
- The interviews and the photos taken by the carer have produced rich and complex stories, which have been edited and reproduced as a book for other carers. ²



² The book can be downloaded from the University of Bradford website

<https://www.bradford.ac.uk/health/dementia/research/caregiving-hope/>

There are a limited number of hard copies available which can be ordered by emailing s.parveen27@bradford.ac.uk

Some extracts from the interviews and photos taken by carers:

Obligation and willingness to care

“I just feel as if it’s been forced upon me, half of me wants to be the good chilled out daughter that says, but she’s my mum and I will do it for my mum, and you know these people who have had their parents live with them, I hold my hands up and say all respect.”

(Anne)³

“I think also we want to look after her. It’s not just a responsibility, we want to look after her, you know because we love her”.

(Laila)

“I do not want to be labelled as my mum’s carer, I want to be my mum’s daughter or as my sister says, I want to just come and visit my mum and just go away. I want to just be the daughter I was, where I can just go and visit my mum, take her out for the day, have lunch, visit a nice house, not have to turn up start doing washing, cooking, cleaning, making sure she’s got social activities sorted out, I don’t want to be labelled an official carer, but I feel what choice do I have?”

(Bridget)

Preparedness

“Well, as soon as it was diagnosed, I began to pick up information, and there was various people I got into contact with, who gave me more information, and I also began to read up about it. I've done a lot more reading and observation of others, through various clubs and groups.”

³ The names of carers have been changed to ensure anonymity.

(John)

“I’ve thought about her future needs. I know there’s a chance that she might become bed bound and maybe she won’t walk, and she’ll forget to walk, she’ll forget to do this and that. It’s a case of well you just have to deal with it. We’ve already brought her bedroom downstairs, because at my mum’s there’s not a bathroom upstairs, the bathroom is downstairs.

The houses along that road, the bathrooms have always been downstairs, so we brought the bed down. My mum and dad have three reception rooms downstairs, and the smaller out of the three has been converted into a downstairs bedroom for her. We always make sure there’s a lamp on at night for her in her bedroom, just little things like that.”

(Laila)

“I’ve always been very optimistic sort of person, and if there’s been a problem I get on with it and do it and sort it out quickly, I don’t mull it over and mull it over and vanish into introspection, I’m very practical and pragmatic and, always been like that, and always been optimistic.”

(Andrew)

“People need to be prepared, they need to have an inner reserve of patience, and somehow recharge the batteries, I know it’s difficult when you don’t want to let go of somebody for a long period, but you need to have, I used to have the, the couple of hours when one of her friends would come and take [wife] out, and maybe I didn’t recharge me battery in the right way at those times, maybe I rushed around and got some jobs done that it would’ve taken me days to do with [wife] as they say ‘in tow’. When you needed emotional support and a break from caring – I think that’s the same.”

(Daniel)

You don’t cope do you? You just biding your time, any peace you would get would be a relief. Ok mums quiet for about 10 minutes, make the most of it kind of thing, and then it would start again. Hours turned into days, and days turned into weeks, that’s how we coped. It was tough. What does coping mean? Like you have a coping mechanism, like you

have a cigarette, do you see what I mean? I don't smoke and I don't drink, I suppose some people do and that's their coping mechanism.
Yeah we just bided time really."
(Hassan)

"It's really hard to know what a journey it's going to be, it's a good job that you don't know. It is a good job because you don't know how much you're going to get angry, I suppose anger, anger and guilt are the two things that I was least prepared for and yet I knew, I knew in the abstract anger and guilt are around hugely but to actually experience the anger and guilt, sometimes the anger towards ***** after repeat question after repeat question and I would say 'Oh shut up, you know I've told you 100 times' and she doesn't understand, she can't help what she's saying. But I would say 'Oh shut up'. That takes you by surprise. I still feel guilty about so many things with ***** , I could have done things so differently, I could have managed things so differently, I could have coped for longer with her aggression than I was doing, if I'd known then, if I'd known what was coming, I would never had had her admitted to hospital, I would never have agreed. I could have protected her in so many ways, there's so many shoulds around, I should have done something, and yet here in the end, you are only human."
(James)



Self-care strategies such as going for coffee with friends or having your hair done were considered important by the carers interviewed. These strategies were useful in reducing stress and giving carers a chance to “recharge their batteries”.



Many carers discussed the need to involve the person living with dementia in daily life activities such as shopping and walking the dog. However, many carers struggled with arranging pleasant activities for the person with dementia and were unsure how to help the person remain socially included and engaged. South Asian carers particularly struggled with the progression of dementia and relied on medication to ease distress in the person with dementia. A number of families also spoke about the need to made adjustments to the home environment to help with the person with dementia.

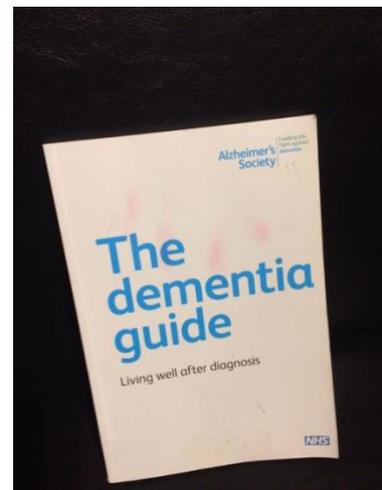


A larger selection of photos and interview extracts are presented in the book “Living with Dementia: The Carer’s Experience”.

What we found: Future carers

- We also asked members of the public to complete a questionnaire to explore how willing and prepared people would feel to support a relative with dementia in the future.
- We received 1100 responses, of which 769 were from a white British background and 232 were from a south Asian background.
- Similar to the carer group, the south Asian group reported stronger feelings of obligation to provide care for elders. They were willing to provide practical support (such as cooking and cleaning for the person with dementia) but were not as willing to provide emotional and nursing support compared to the white British group.

- The south Asian group also held negative views of dementia and were unprepared to provide care in the future.
- Overall, we found that a positive attitude towards dementia, and a higher willingness to care were associated with better preparedness to care in the future.
- We also conducted discussion groups with over 50 members of the public from a variety of backgrounds. Most people felt they lacked information about dementia, and had not planned and felt unprepared to provide care in the future. They assumed that they would receive support in caregiving from other family members and that there would be good services and financial support available to support them.



Summary and Next Steps

- The majority of the carers included in this study were experiencing high levels of burden, anxiety and depression. It is vital that support services are developed and delivered to meet the needs of carers.
- High levels of burden and low mood, influence willingness to care (that is, lead to reluctance to care) which may result in poorer quality of life for the person with dementia.
- The UK care system relies on relatives to provide support to people living with dementia, saving the NHS £11 billion per year. In order to sustain this “care in the community” strategy, families need to be supported in their role.

- South Asian families may feel culturally obligated to provide care for their elders, but they are not always willing and prepared, leading to higher levels of burden. Health care professionals should be aware of this sense of obligation and offer culturally sensitive support (as opposed to assuming south Asian families do not require support due to cultural obligation).
- The results of the study suggest that a sense of preparedness is important for a positive caregiving experience. Our next steps are to design support packages that aim to improve preparedness and confidence in managing the different aspects of dementia.
- We have used anonymous extracts from the interviews and the photos to compile a book for carers. The book provides tips and presents various experiences of providing care and is available in print and online.
- The findings based on the questionnaires from members of the public suggest that future generations are unprepared for caregiving, hold negative views of dementia and have high expectations of services. We need to provide information and do further awareness work to improve public knowledge and understanding but also take a proactive approach to developing much needed services.

Thank you to everyone who contributed towards this research.

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