

Identifying research priorities about older carers

Project team

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The project

The project ran from January to August 2018. Our intention was to explore the experiences and research priorities of older (70+ years), unpaid, family carers from the perspectives of both older carers themselves and also the volunteers and professionals who work with them.

This summary provides an overview of what we did and what we found.

Who supported the project?

The Wellcome Trust funded the project and Kingston Carers Network and Carers Support Merton recruited carers and volunteers and professionals for our discussion groups. We also had an advisory group who gave us invaluable support throughout the project.

Who took part?

Carers

Forty-four carers aged over 70 years old took part in the discussion groups. Most were White British and most were currently caring, although a few were former carers. They had been providing care for an average of 20 years but some had been caring for many decades. Two-thirds were supporting a partner and most of the remainder were caring for adult children. They were caring for people with varying conditions including dementia, mental illness and physical and learning disability.

Volunteers/professionals

Thirty-five volunteers and professionals took part. Most worked in the voluntary sector and had been working with older carers from between 4 months and 26 years (average 7 years) and had a variety of roles, such as: carers' support workers, chief executive officers, wellbeing and inclusion coordinator, commissioning manager, carers hub manager and volunteers.

What did we do?

We held 8 discussion groups with carers and volunteers and professionals. These lasted between 1.5 and 2 hours. There were 4 separate groups with carers and 4 with volunteers and professionals. We also had a small, final discussion group with carers where we told them about what we had found and asked them to help us decide what research priorities we should focus on in future studies.

What did we learn?

Our study suggests that older and younger adult carers have many similarities both in the rewards of caring and in the challenges they face.

'We've grown together as a family, it's been, you know, in spite of it all it seems, you know, that it's been a positive experience for us as a family.' Carer

However, some challenges were seen as greater for older carers and they also have some differing needs when compared to younger carers. For example, older carers' own physical and mental

health has a huge impact on their experiences and the support they need. Their health also means that they are often more worried than younger carers about the future – about what happens when they can no longer care.

'I'm approaching my 82nd birthday, so all my strength has disappeared, but not only my strength, my mind is disappearing as well.'
Carer



What were the implications of what we found?

The age of older carers and sometimes deteriorating health can result in a loss of energy and stamina, which may affect their ability to provide care. This loss of energy can make it difficult for older carers to find out about services and to have a life outside of caring. Their age and health concerns cause worry about the future and what will happen if they die suddenly or are unable to care.



'I was thinking as you get older it's a lot scarier, you know that you are that one step nearer the end of your journey, and what exactly is going to happen after you've reached that end?... What on earth happens to the person you're caring for?' Carer

Older carers reported they are more likely than younger carers to be lonely and isolated due to their caring responsibilities and their own ill-health, which prevent them from leaving the house. As a result, they often lose touch with friends and family, further increasing social isolation. In particular, caring for someone living with dementia was seen as especially isolating due to the loss of the relationship with the person being cared for and difficulty in taking part in social activities together.

'...just so lonely, before I always go to the church, helping people, but now I just cannot ... it's so difficult, [to] go to my neighbour, [to] have a tea or coffee, you can't...' Carer

Finding out about and accessing support and services were described as particularly challenging for older carers. They gave a number of different reasons for this, for example, some services only advertise on the internet and social media which they often have difficulty accessing, or their own ill-health and loss of stamina make contacting services especially demanding. Remaining independent, a strong sense of duty to provide care without help and not expecting support were all discussed as also reasons for not accessing services. Many also did not want to bother their friends or families who they perceive as having their own busy lives.

'...how can I ask my daughter who works five days a week and who's got two sons to bring up and who's got a house and a dog and what about my son who is a drunk and doesn't want to come home and look after his dad' Carer

What are the priorities for older carers research?

The final group identified a number of priorities for change in order to improve the lives of older carers. The following three were ranked most highly:

- 1) Making it easier for older carers to know about, access and use services to help reduce the 'burden' of accessing services
- 2) Addressing social isolation, loneliness and psychological issues in older carers
- 3) 'What happens to my loved one when I die or suddenly cannot care anymore?'

Where next?

Towards the end of the project we brought together a variety of people including older carers, volunteers, researchers and voluntary and statutory sector managers. From the discussions at the event we have been able to identify research projects to improve the lives of older carers. We plan to work together to apply for funding to explore these ideas in detail and perhaps develop services specifically aimed at supporting older carers. In future studies we will talk to a wider range of older carers to include those who are housebound as they were unable to attend our discussion groups.

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