

Understanding the experience of caring for a friend or family member after their stroke – a research study

Summary report of study findings

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Report written with the help of carers and family members of stroke survivors

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Contents

	<i>Page</i>
Introduction to the report.....	1
Background to the study.....	2
Who was involved in this research study?.....	2
Study aims and questions	3
The study process	4
Who took part?	5
Summary of findings	6
What are the next steps?.....	13
How can I find out more?	14

Please note, the term “carer” is used throughout this report to refer to anyone who has provided support or care to a loved one following a stroke. However, we acknowledge that people may not describe themselves this way and we present findings on that issue.

Introduction to the report

What is the purpose of this report?

This is a summary report of a research study exploring informal caregiving following stroke. We provide information about the purpose of this study, followed by our main findings.

We hope this report provides a helpful understanding of this study and what we plan to do next.



Image Description: A stack of spiral bound notebooks

Why have I received it?

You have been sent this report if you kindly took part in the research study and agreed to receive a summary report of the study findings.

Alternatively, you may have helped share the adverts for this study and expressed an interest in receiving a summary of the findings.

We express our sympathies to anyone bereaved since this study was completed.

If you have any questions about this report or need support to understand it, please contact us using the details on the front cover.

Background to the study

After experiencing a stroke, people often need additional help and support. This care and support can often be provided by family and friends. Some family members and friends adopt this care-providing role quickly. Others can find it more difficult to see themselves as a 'carer', and do not access support within this role.

Little is currently known about how and when people start to see themselves as 'carers' or someone in a care-providing role, and also about people's preferences around care-related language (e.g. carer, caregiver, family member). Understanding these areas more could help services to offer better support.

Who was involved in this research study?

The main researcher completed this project as part of their Doctorate in Clinical Psychology qualification, alongside two researchers at the University of Manchester.

A small group of individuals with experience of providing care and support to a friend or family member after their stroke, helped in various ways throughout this project. This included planning the project, understanding and sharing the findings.



Image Description: A marker next to white speech bubbles

Study aims and questions

Overall, the aim of this research study was to develop our understanding in several areas that previously had very little research around them. We aimed to provide recommendations that could improve support offered to informal carers of stroke survivors.

We aimed to answer three questions:



1) How and when does someone see themselves as a 'carer' or self-identify as a person providing care to someone after stroke?



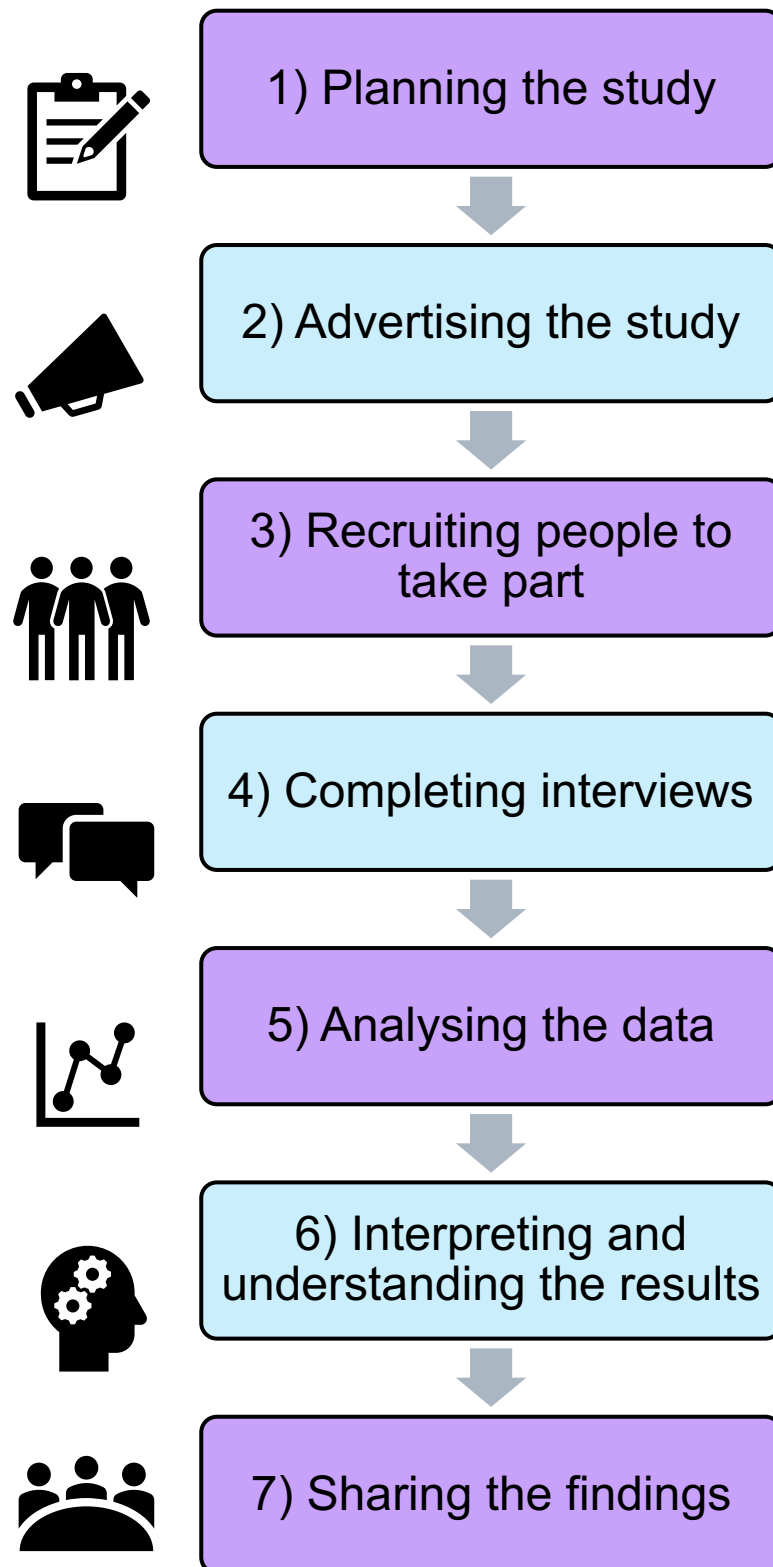
2) What care-related language have participants experienced and what are their preferences around this?



3) What has the experience of support been for participants?

The study process

The diagram below shows the main stages that were involved in this study



Who took part?

Anyone who had provided support to a friend or family member after their stroke was able to participate.

18 carers from the UK took part in the study.



Most carers identified as female (72%).



Their average age was 58 years but ranged from 19 to 92.



Relationships of the person taking part in the study to the stroke survivor included:

- 10 spouses/partners
- 1 brother/sister
- 5 sons/daughters
- 1 grandson/granddaughter
- 1 friend



People who took part identified with a range of ethnicities:

- White British (89%)
- Mixed ethnicity, White British and Black African (6%)
- Asian (6%)



Some people had experienced providing care and support prior to the stroke (44%).

Summary of findings

In summary, this research study was the first of its kind to explore the self-identification process of informal carers of stroke survivors.

We developed a better understanding of how and when people start to see themselves as a 'carer' or in a care-providing role. This included factors that helped with this self-identification process, and some that made it more challenging.

We have also developed a better sense of people's preferences around care-related language.



Image Description: A close-up photograph of two people holding hands

Question 1

We asked: How and when does someone see themselves as a 'carer' or self-identify as a person providing care to someone after stroke?

We found 3 things:

- 1) Things that help someone see themselves as a 'carer' or self-identify as a person providing care to someone after a stroke
- 2) Things that make this difficult
- 3) Information about when the person first recognises themselves within this care role

Things that helped people to identify with the care-providing role included:

- ***Being involved in the stroke survivor's rehabilitation*** – seeing or being made aware of the stroke impact
- ***Accessing peer support and connecting with others in a similar situation***
- ***Recognition from others*** – people often struggled to recognise their changed role by themselves, and needed others to support them to recognise this
- ***Changes to family systems and dynamics*** – including in their relationship with the stroke survivor and within the wider family system
- ***Increased sense of responsibility and feeling they were the only person able to adopt the role***
- ***Learning new skills and responsibilities (e.g. adapting communication, motivating the stroke survivor)***
- ***Advocating for the stroke survivor and their needs***
- ***Positive aspects of caregiving-***
experiencing a sense of pride or achievement in supporting their loved one, or the strengthening of their relationship with them



Image Description: A close-up of a person holding a small exercise ball and someone supporting them



Image Description: Close up photograph of small, coloured person-shaped pieces with connecting lines between



Image Description: Two people sitting together with one writing in a notebook

Things that made it difficult for people to identify with the care-providing role included:

- ***Sudden increase in responsibility and life feeling too chaotic to recognise own needs and changed role***
- ***Care role being dynamic and changing depending on the stroke survivors' needs, which took time to process and adjust to***
- ***Reduced understanding between formal (paid) and informal (e.g. family, friends) carers***
- ***Having a specific idea of what a 'carer' is that doesn't match their own experiences***
- ***Inappropriate use of care-related language (e.g. not culturally accessible or appropriate; terms not explained; terms used before person had adjusted to care role)***
- ***Feeling adopting the "carer" role was a permanent change to their identity instead of something that may change throughout stroke trajectory, depending on their loved one's needs***
- ***Expectations and assumptions by others that they would take on the 'carer' role, without considering their preferences***
- ***Lack of recognition and validation from other people of their changed role- including societal stigma around little understanding on difference from paid care role***

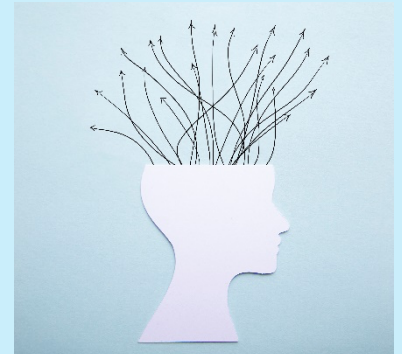


Image Description: Image of a head with lots of arrows coming from it in many directions



Image Description: Five square speech bubbles in various colours

In exploring *when* participants started to identify with the care role, this first point of seeing themselves as holding a care-providing role happened at different points along the stroke trajectory.



Image Description: A clock and notepad on a colourful surface

There were four key points that people spoke about:

- 1) ***Stroke event***- an instant recognition at the time of the stroke event
- 2) ***Discharge planning stage***- realisation of the forthcoming changes in role and responsibility at point of planning discharge from hospital
- 3) ***Initial return home from hospital***- on initial return home from hospital
- 4) ***Later stage in caregiving***- at a later stage when the stroke survivor had resided in the home environment, and they had been providing care for a while

Question 2

We asked: What care-related language have participants experienced and what are their preferences around this?

We found two main opinions around the use of care-related language (e.g. carer):

Opinion 1:

- One group of people liked terms such as “carer”, and would use them to describe themselves.
- They felt these terms were broad and captured the different elements that the role may involve. This included acknowledging that their role now included responsibilities that they did not have before the stroke.
- This group also discussed how they identified with the care role as well as their relationship role with the person. They felt acknowledging the additional ‘carer’ role was important to them.

Opinion 2:

- Other people did not like care-related language (e.g. carer) and would not use it to describe themselves.
- There were lots of reasons for this which can be found in the earlier section about 'things that made it difficult' for people to identify with the care-providing role.

Examples include:

- People worried that if they saw themselves as a 'carer', this may impact their relationship role with their loved one.
- Some people had an idea of what a "carer" was that didn't match their experiences.
- 'Carer' not always culturally appropriate or accessible, or the stroke survivor may have a negative view of these terms.

Everyone, even people who disliked these terms, agreed the need to use terms such as 'carer' **to help other people (e.g. healthcare professionals) understand their role/identity.**

They also spoke about using these **terms to make sure that their own views and opinions were included and respected** in the rehabilitation and support of the stroke survivor.

Many people who disliked the term 'carer' found it **difficult to think of an alternative.** Because this term is so widely used, they felt **a sense of powerlessness** to change this and to make other people aware of their own preferences around these terms.

Question 3

We asked: What has the experience of support been for participants?

People spoke about different types of support they found helpful. These included:

- **Friends, family, local community**
- **Peer support** and connection
- **Indirect** (e.g. through stroke survivor accessing support)
- Posters and **informational** resources



Image Description: Stick figure people holding hands

Lots of helpful suggestions were made for how to improve support for those providing care and support to someone after a stroke:

- **Signposting** to resources and support
- **Accessibility** of information
- Information on **practical support** (e.g. carer's allowance)
- **More variety** in support options (e.g. remote/online)
- **Improved communication** between informal carers and healthcare services



Image Description: Directional sign with colourful arrows

What are the next steps?

This research project has now finished. We are committed to sharing the findings and learning we can take from this study.

The lead researcher successfully passed their viva examination, which required them to discuss and defend this research project.

This report has been shared with people who took part in the study. It has also been shared with stroke services and third sector organisations to help them provide better support to carers.

We hope that our findings will inform services as to how support for carers of stroke survivors can be improved, to better meet their needs.

Our next steps to work towards this include:



Sharing the study findings with more stroke services and third sector organisations (including sharing this report and offering to give talks).



Attending research and academic conferences to further share the findings.



Sharing this work with other researchers and healthcare professionals in science journals.

How can I find out more?

If you have any questions about the study or would like to get involved in any future similar research projects, feel free to contact us using the details below:

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We would like to express our sincere thanks to everyone who participated in and supported this research project.

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