

**INTRODUCTION**

Stroke is the second leading cause of death and third most prevalent cause of disability burden globally (Feigin et al., 2017).

Most people who have had a stroke are dependent on informal caregivers for daily living (Forster et al., 2013).

So far, research has focused mainly on the impact on stroke survivors, rather than on the impact on caregivers, who are an essential component in successful rehabilitation (Busetto et al., 2022).

**AIMS AND OBJECTIVES**

**Aim:**

- 1. To explore carer experiences of information and service provision following hospital discharge, whilst identifying their needs and how support is best offered to them.

**Objectives:**

- 1. To explore carer experience as fundamental to a stroke survivors' rehabilitation whilst gathering information on current pathways of referral
- 2. To explore carer experience of information and service provision at the point of and following hospital discharge, as part of their transition to community-based chronic stroke rehabilitation
- 3. To explore what carers need and describe as being of most value to them in terms of engaging with community-based rehabilitation after hospital discharge
- 4. To investigate how deprivation impacts on the experiences of stroke-related service provision for carers of stroke survivors



Flowchart demonstrating the recommended pathways of referral after the onset of stroke (taken from NICE: stroke rehabilitation, 2021)

**METHODOLOGY**

Design: Qualitative cross-sectional study

Pilot interview conducted with career of a stroke survivor to develop guide questions

Ethical clearance received from Newcastle University Ethics Committee

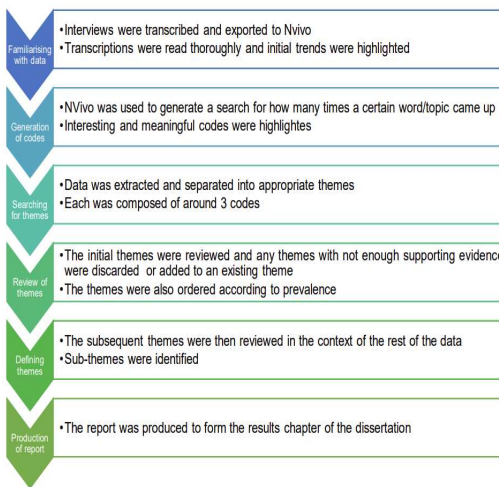
Participants, recruitment and data collection:

- N = 11 carers attending Teesside Stroke Club
- 1:1 semi-structured interviews up to 45 mins

Participant number	Gender	Age	Ethnicity	Area (LSOA)	Area IMD Rank	Area IMD Score
2	Male	65+	White British	Redcar & Cleveland	-	-
3	Female	65+	White British	Middlesbrough	856	1
10	Female	45-54	White British	Middlesbrough	127	1
1	Female	65+	White British	Redcar & Cleveland	12050	4
7	Female	65+	White British	Middlesbrough	12573	4
5	Male	65+	White British	Middlesbrough	15731	5
9	Female	65+	White British	Hambleton	14485	5
4	Female	65+	White British	Middlesbrough	24662	8
8	Female	55-	White British	Middlesbrough	26274	8

Broad topics covered:

- Information provision at discharge
- Services received
- Perceptions and experience of the services received
- What life is like now



**RESULTS**

Ten out of eleven carers interviewed had a negative experience of information and service provision. The thematic analysis generated four main themes.

Higher order themes	Quotes
<b>Carer's lives have been changed by stroke</b>	<ul style="list-style-type: none"> <li>• "It's totally affected my life. I had to retire to look after my mum" (Participant 8)</li> <li>• "We could go on holiday but of course that's all gone now [...] our life has changed so much" (Participant 2)</li> </ul>
<b>Loneliness and impact on relationships</b>	<ul style="list-style-type: none"> <li>• "We can't talk to each other" (Participant 6)</li> <li>• "When you were away practically every weekend and you had a lovely social life and you know, we used to dance, we used to do all that, and it all stops" (Participant 1)</li> </ul>
<b>Negative experiences of hospital discharge</b>	<ul style="list-style-type: none"> <li>• "They didn't even give me a pack, nothing. Nothing written down" (Participant 10)</li> <li>• "If I had information, I could do something about it" (Participant 2)</li> <li>• "All the way through it was honestly like trying to draw teeth trying to get information" (Participant 2)</li> <li>• "There wasn't much thought" (Participant 7)</li> </ul>
<b>Feeling abandoned</b>	<ul style="list-style-type: none"> <li>• "Until the blocks are put in place, the carers are pretty much left and you're hanging on a limb" (Participant 2)</li> <li>• "I don't think anybody asked me how I was doing" (Participant 8)</li> </ul>

**REFERENCES**

Busetto, L., Sert, M., Herzog, F., Hoffmann, J., Stang, C., Amiri, H., Seker, F., Purrucker, J., Mundiyanapurath, S., Ringleb, P.A. and Nagel, S. (2022). "But it's a nice compromise"—Qualitative multi-centre study of barriers and facilitators to acute telestroke cooperation in a regional stroke network." *European journal of neurology* 29(1): 208-216.

Feigin, V. L., Norrving, B., and Mensah, G.A. (2017). "Global burden of stroke." *Circulation research* 120(3): 439-448.

Forster, A., Dickerson, J., Young, J., Patel, A., Kalra, L., Nixon, J., Smithard, D., Knapp, M., Holloway, I., Anwar, S., and Farrin, A. (2013). "A structured training programme for caregivers of inpatients after stroke (TRACS): a cluster randomised controlled trial and cost effectiveness analysis." *The Lancet* 382(9910): 2069-2076.

NICE (2021). *Stroke Rehabilitation*, National Institute for Health and Care Excellence: 1-15.

Williams, E., Buck, D., Babalola, G., Maguire, D. (2022) What are Health Inequalities? From <https://www.kingsfund.org.uk/publications/what-are-health-inequalities>.

**CONCLUSIONS**

Carers were not provided with adequate information and there is inconsistency amongst the pathways of referral following hospital discharge.

Although a distinct trend between deprivation and information and service provision after stroke has been identified, this study does support the idea that people living in more deprived areas are more likely to experience poorer healthcare service quality and provision (Williams et al., 2022).

More must be done to support carers including provision of more information on discharge that will in turn better prepare them for their role. With around 1.3 million people living with stroke today, it is vital that carers access appropriate information and services in order to decrease caregiver burden and aid them as they adapt to the caregiving role.