Organising Support for Carers of Stroke Survivors (OSCARSS): Progress update from an ongoing Cluster Randomised Controlled Trial (cRCT)

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Family and friends of stroke survivors often take on the role of informal caregiver to support personal care and daily living. In the UK, informal caregivers for stroke survivors provide care worth up to £2.5 billion per year at great personal cost^{1 2}. Identifying and addressing the needs of informal caregivers is a priority at a national level but there is uncertainty about how best to do so^{3 4}.

AIM OF OSCARSS

The primary aim is to determine the clinical and cost **effectiveness** of a new intervention for identifying and addressing carers' needs, when **compared** to a **control** of standard Stroke Association practice.

INTERVENTION

An evidence-based model involving carer-led, staff-facilitated needs assessment and support.

The model was originally developed in the context of palliative care and was adapted for stroke by researchers and carers.

It was tailored for implementation within Stroke Association services, including staff training.

METHODS

Mixed-methodology, longitudinal, multi-site **cRCT** with **health economic** analysis, **qualitative** interviews and embedded **process evaluation**.

Clusters are Stroke Association services randomised to the new approach (intervention) or standard practice (control). Staff training is completed and adult carers referred to clusters and seen by trained staff are invited to participate.

Primary outcome measure at 3 months

- Caregiver strain subscale of the Family Appraisal of Caregiving Questionnaire (FACQ)

Additional outcome measures at 3 and 6 months

- Caregiver distress and positive caregiving appraisals subscales of the FACQ
- Pound Satisfaction with Stroke Services Scale
- Hospital anxiety and depression scale (HADS)
- EQ-5D-5L
- Service receipt inventory (Health and Social care)

REFERENCES

- Luengo-Fernandez et al. (2006) "Cost of cardiovascular diseases in the United Kingdom." Heart 92(10): 1384-9
- Saka, O., A. McGuire, et al. (2009). "Cost of stroke in the United Kingdom." Age Ageing 38(1): 27-32
- Legg, L., T. Quinn, et al. (2011). "Non-pharmacological interventions for caregivers of stroke survivors." Cochrane Database of Systematic Reviews 2011, Issue 10. Art. No.: CD008179.(DOI: 10.1002/14651858.CD008179.pub2.).
- NHS England (2014). NHS England's Commitment for Carers. M. d. a. N. directorate.

STUDY PROCESS

PROGRESS

- 17 control & 18 intervention clusters trained & referring since Jan 2017
- Two rounds of questionnaires exploring carer support practises have been completed with Stroke Association staff :
 - Sept 2016 (pre-randomisation) 67 staff from 34 known clusters
 - Aug 2017 (after training and recruitment commenced): 41 staff from 27 clusters

Carer recruitment

As of 1st May 2018:

- 367 carers have been recruited
- 282 carers have returned 3 month (primary) outcome measures
- 176 carers have returned 6 month (follow up) outcome measures
- 26 qualitative interviews with carers have been completed

The Carer Research User Group (RUG)

Carers from a study-specific RUG have worked in partnership with the research team; meeting regularly since Dec 2015. In addition to **co-developing the intervention**, the RUG has supported development of:

- study design, documentation & processes
- choice of **outcome measures**
- staff training** packages
- strategies to boost **recruitment**

A RUG member sits on the Trial Management Group and the RUG gives feedback to our independent Trial Steering Committee.

OSCARSS is on target!

By July 2018 we aim to have recruited **400 carers** to cRCT

Results due 2019

Trial Info

Ethics secured: Sept 2016 (16/NW/0657)

ISRCTN registration: 58414120

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Stroke
association