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Title: “I feel dumb, embarrassed, and frustrated”: A qualitative exploration of the lived experience of acalculia.

Introduction: Acalculia is an acquired disability following stroke or brain injury, which involves difficulty processing numerical information (e.g. phone numbers, measurements) or problems with calculations and understanding quantities. Acalculia is not routinely screened for as part of standard post-stroke assessment. As a result, there is a lack of understanding of the nature and prevalence of post-stroke acalculia, and the impact it has on stroke survivors. This qualitative study aimed to explore stroke survivors’ experiences of acalculia. Stroke survivors with a strong interest in acalculia and its rehabilitation initiated the study and contributed to its design.

Methods: We explored the impact of acalculia on the lives of 16 stroke/brain injury survivors with acalculia and 7 carers using semi-structured online interviews. Participants ranged in age, gender, time post onset, lesion localisation, country of residence and numeracy level prior to brain injury. Data were analysed using thematic analysis.

Results: Three main themes were identified: Awareness and Diagnosis, Emotional and Physical Impact, and Coping Strategies and Independence. Participants and carers repeatedly referred to the lack of awareness and treatment for acalculia and the devastating impact acalculia has had on their lives and independence. Practical impacts included managing money, making appointments, using timetables, organising social activities and employment, and managing medication.

Conclusions: Our results highlight the urgent need to develop suitable assessments and interventions for acalculia and the scope for this to be PCPI-led. The data also reveal useful strategies and suggestions regarding effective timing and approaches for intervention.

(240 words)

“I feel dumb, embarrassed, and frustrated”

A qualitative exploration of the lived experience of acalculia.

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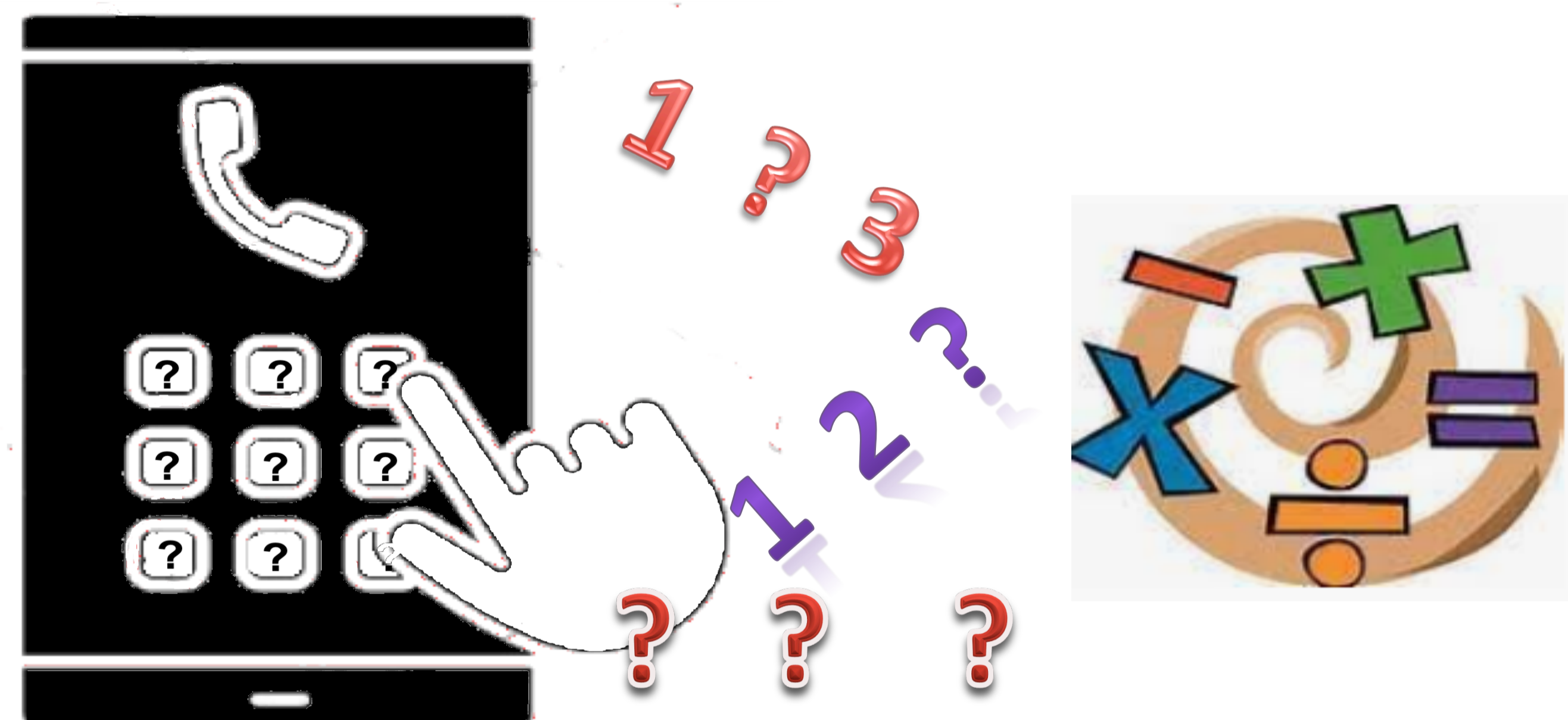
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INTRODUCTION:

- **Acalculia** is an acquired disability following stroke or brain injury,
- it involves **difficulty processing numerical information** (e.g. phone numbers, measurements) or problems with **calculations** and understanding **quantities** ⁽¹⁾.
- it is **not routinely screened** as part of standard post-stroke assessment.
- as a result, there is a **lack of understanding of the nature and prevalence** of post-stroke acalculia, and the impact it has on stroke survivors.

Aim of this study:

To explore stroke survivors' experiences of acalculia.



METHODS:

- We explored the impact of acalculia on the lives of **16 stroke/brain injury survivors** with acalculia and **7 carers** using semi-structured online interviews.
- Participants were recruited via twitter, support groups and word of mouth.
- Video Interviews data (mean time=56min, SD=31) were analysed using **Thematic Analysis** ⁽²⁾.

References: 1. Ardila, A., & Rosselli, M. (2019). Cognitive Rehabilitation of Acquired Calculation Disturbances. *Behavioural Neurology*, 2. Braun, V & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2).

Theme 1: Awareness and Diagnosis

Participants with acalculia described **not being fully aware** of their difficulties at first, as they had to initially deal with **mobility** and **language** problems.

Awareness emerged gradually, trying to return to independent life: *“Well, for for a long time, I thought...oh, numbers it's alright...I didn't notice anything because I think [carer] did everything for me really.... so like, the bank...shops, it's only erm phone and...you know, six digits and and I thought oh I just couldn't, I just couldn't do it...that's the first time that I thought actually maybe numbers is are are a bit different now”*

Support for acalculia was very limited: *“So I asked, therapists, what about my maths? What you can you do for to help me with my maths? Every therapist I've met, says, 'I can't help you'. Why? Because it's not part of their training.”*

Theme 2: Emotional and Practical Impact

Acalculia had a profound emotional impact: *“I'll get angry and frustrated and sometimes I say oh god I'm rubbish... I feel, I'm sorry. I feel sad” (P2 cries).*

Carer: “Sometimes you say you're 'thick'.”

Acalculia impacted negatively on every aspect of daily life:

Dates: *Carer: “(she) can't even say that she was born on the 9th of the 10th 1964”.*

Travel: *“I can't plan a journey by using the time tables”*

Cooking: *“Microwave cooking times are a jumble with numbers. Okay?”.*

Medication: *“...I'm totally relying on the pharmacist that they will get it right”*

Theme 3: Coping Strategies and Independence

ALL participants mentioned the lack of professional support they received: *“No one has helped me with coping strategies”*

But **ALL** had developed their own strategies.

The most common strategy was using **fingers to count** but some also used **apps**:

“I do use an app (Tip Calculator) for calculating tips in restaurants”

Despite this, acalculia impacted independence and confidence:

“I depend on my parents for handling my money and most other things dealing with numbers”

“My girlfriend goes shopping with me...I can't cope with that at all.”

CONCLUSION: There is a substantial unmet clinical need for management of acalculia which

common and debilitating after stroke, across the severity range. Acalculia seems to fall between **professional roles** in stroke care. The findings highlight the need to develop sensitive, efficient **assessment** and **intervention** tools. There is huge potential for **technology** use, and **pen & paper** strategies also have a role. This project was initiated by **stroke survivors with acalculia**, highlighting the scope for this work to be **PCPI-led**.