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A qualitative study into the experience of living with acalculia after stroke and other forms of acquired brain injury

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ABSTRACT

Acalculia, an acquired disability following a brain injury, involves difficulty processing numerical information and/or calculations. Acalculia is not routinely screened for, and as a result there is a lack of understanding about the nature and prevalence and the impact of the condition. This qualitative study was initiated by stroke survivors with a strong interest in acalculia. Sixteen stroke/brain injury survivors with acalculia and seven carers were interviewed using semi-structured online interviews. Participants ranged in age, gender, time post-onset, country of residence and numeracy level prior to brain injury. Data were analysed using thematic analysis. Three main themes were identified: Awareness and Diagnosis; Emotional and Practical Impact (independence); Support, Coping Strategies and Self-training. Participants and carers repeatedly referred to the lack of awareness and treatment for acalculia and the impact acalculia has had on their lives and independence. Practical impacts included managing money, making appointments, using timetables, organizing social activities and employment, and managing medication. Our results highlight the urgent need to develop suitable assessments and interventions for acalculia and the scope for this to be Patient, Carer and Public involvement (PCPI)-led. The data also reveal useful strategies and suggestions regarding effective timing, targets and approaches for intervention.

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Introduction

Acalculia is an acquired cognitive impairment following brain injury (Ardila & Rosselli, 2002; 2019). Symptoms include difficulties with number and calculation processing, which could manifest in difficulties understanding or producing numbers (whether in verbal or written form, e.g., telephone numbers/ addresses) or in understanding and processing concepts of quantity. Despite the potentially devastating impact on patients and their family life, acalculia remains a neglected area of postbrain injury care, and there is little understanding of the impact it has on patients' and carers' lives, or how they could be better supported to deal with these symptoms.

The Triple-Code Model (TCM) for mathematical processing, as introduced by Dehaene (1992), has dominated research on arithmetic over the last 30 years. The TCM suggests that there are three "codes" by which numerosity (an inclusive term referring to the property of indefinite quantity of units) may be processed (for a recent review evaluating the model based on neuroimaging and behavioural findings, see Siemann & Petermann, 2018). The three codes, as proposed by the TCM are as follows:

1. Preverbal system of arithmetic reasoning: enabling quantity estimation and magnitude comparisons, considered a "core mechanism", which is homed within the bilateral parietal region (Benn et al., 2012; 2013; Cohen Kadosh et al., 2008). A magnitude processing deficit can result in difficulties understanding quantities (e.g., that 52 is smaller than 60), and with difficulties estimating quantities (Dehaene et al., 2003).
2. Verbal code ("thirteen"): enables the production of number words in spoken and written language forms, and the retrieval of stored pre-learned mathematical facts, such as simple addition and multiplication tables. This function is facilitated by the left perisylvian structures, and connected to core magnitude regions via the left angular gyrus (Benn et al., 2012; Dehaene et al., 2003). Damage to this unit can result in difficulty verbalizing, writing or reading number words (e.g., McCloskey et al., 1986). It can also affect access to linguistically stored mathematical facts (e.g., multiplication tables, van Harskamp et al., 2005) and affect calculation speed/accuracy (e.g., Benn et al., 2013).
3. Visual (Arabic) number form ("13"), enables any handling of digits, including production of written numbers, multi-operation calculation and parity decisions, relying on bilateral parietal regions (Dehaene et al., 2003). Deficit in this unit will result in difficulties producing and reading digits, and is often associated with visuo-spatial aspects of numerical processing, such as malalignment of numbers and columns (e.g., Cohen & Dehaene, 1991).

However, this theoretical knowledge has not been translated into clinical care. Acalculia is overlooked in current clinical practice and is absent from the UK (NICE, 2016; 2019) and many international clinical guidelines. The lack of focus on acalculia within stroke and brain-injury services is reflected in the sparse evidence base relating to clinical assessment. Recently there has been more interest in the topic, resulting in several assessments being developed. One French [Villain et al., 2015] clinical assessment for acalculia has not yet been translated into English. Two English language assessments are also now available; The Oxford Cognitive Screen (Demeyere et al., 2015) includes some numerical skills questions, and the Numerical Activities of Daily Living (NADL, Burgio et al., 2022; Semenza et al., 2014) is a dedicated test for numerical competence. However, neither of these tests has yet been adopted as routine assessments in post-stroke or brain-injury process, and as a result, there are no official figures about the prevalence of acalculia. Recent epidemiological data suggests that post-stroke acalculia is a common condition affecting between 30% and 60% of stroke survivors (Moore & Demeyere, 2022; Zukic et al., 2012). This is comparable to aphasia, an acquired language disorder, which currently affects a third of stroke patients (Stroke Association, 2018), and unlike acalculia, is extensively assessed, treatment is recommended in clinical guidelines, and is therefore promptly treated following a stroke and other forms of brain injury. To illustrate this point, the Cochrane review of speech and language therapy for aphasia reported the results of 57 RCTs in 2016 (Brady et al., 2016).

This disparity between treatments for language and mathematical disorders is mirrored in the developmental domain, where dyscalculia is relatively neglected, with teachers feeling unable to assist students with numerical difficulties (Sezer & Akın, 2011). This lack of support for numerical difficulties could be at least partly attributed to social stigma in many western countries (including the UK and US), where saying “I can’t do maths” is deemed socially acceptable, while saying “I can’t read” is not (Kowsun, 2008). Maths is also seen as the remit of “mad scientists”, “nerdy” boys, and the socially inept (Epstein et al., 2010). Such attitudes may contribute to low numeracy skills in the general population. For example, a recent survey suggests that 56% of the UK working-age population have numeracy skills at a level that is expected of a primary school child (National Numeracy, 2019). This is true even among highly educated individuals (Lipkus et al., 2001) and health professionals (Estrada et al., 1999; Sheridan & Pignone, 2002).

Low levels of numeracy skills in the general population make identifying post-stroke acalculia more difficult. Varying expected levels of numeracy also make it difficult to predict recovery, as recovery is likely to depend on pre-injury engagement with numerical concepts. Nevertheless, despite the potentially negative impact of low numeracy among healthy adults on health outcomes (e.g., Nelson et al., 2008) and financial decisions (Lusardi, 2012), little attention has been given to the impact of acalculia on patients and their carers, and little is known about how clinical services and charities could provide suitable support. Therefore, the current study explored the impact of acalculia on the lives of brain injury survivors.

The current study was initiated and motivated by the work of two stroke survivors with an interest in mathematics education and/or experience of acalculia. Our work explored the impact of acalculia on the lives of stroke and other forms of brain injury survivors with acalculia and their carers, in order to understand where they faced difficulties, and how these could be addressed to support future patients with acalculia.

Methods

The study received ethical approval from Manchester Metropolitan University Faculty of Health Psychology and Social Care ethics committee, Ref Number: 22246.

The study involved a descriptive qualitative design (Sandelowski, 2000) that was informed by an interpretivist framework (Creswell, 2013). We collected data relating to the impact of acalculia using individual semi-structured interviews with 16 stroke and other forms of brain-injury survivors with acalculia (mean length of patients' interviews = 56 min, *SD* = 19 min) and seven carers (mean length of carer's interviews: = 61 min, *SD* = 42 min). Despite some patients having severe aphasia, which can make participating in interviews difficult, individual interviews were chosen as they result in rich data, allowing participants to answer the questions in a personal manner, and in-depth when possible (Willig, 2013).

The research team

The research team was composed of Psychology and Speech and Language Therapy researchers, and stroke survivors with an interest in acalculia. The interviewer (third author) was a male post-doc researcher, with extensive experience of working with stroke and other forms of brain injury survivors. All authors apart from the sixth author were involved in study design (including the stroke-survivor partners). Data analysis and write-up were conducted by all authors, with the first author writing the first draft of the manuscript. We engaged in reflexive analysis throughout the process of designing the study, collecting, analysing and interpreting the data, as suggested by Finlay and Gough (2003).

Participants

There were 23 participants in total: 14 with a diagnosis of stroke, one with acquired brain injury associated with haemorrhage followed by surgery, and one with Traumatic Brain Injury (TBI) (7 males, 9 females) with acalculia, and 7 carers (3 females, 4 males). Fifteen participants with acalculia also reported aphasic symptoms. Patients ranged in age (mean = 58 years, *SD* = 12.95, range: 32–74 years), time post onset (mean = 7.39 years; *SD* = 6.52, range: 2–27 years), country of residence (UK and US), self-reported severity of aphasic symptoms, and self-reported numeracy level prior to brain injury (from not very good to mathematics degree). Carers ranged in their role (parent/partner), but no demographic information about these individuals was collected as it did not seem necessary. See Table 1 for details.

Sample size was based on reaching data saturation (Guest et al., 2006), such that data were collected until little or no new themes were identified within participant responses. Considerations were also given to information power (Malterud et al., 2016), and sample size was partly guided by previous qualitative work with stroke survivors (Kitson et al., 2013; *N* = 15 stroke survivors; Feldner et al., 2020; *N* = 8 stroke survivors, and *N* = 2 carers). Participants were recruited by approaching third-sector support groups for stroke and brain-injury survivors in the UK, and by advertising on Twitter. Participants had to be adults over the age of 18, who previously had a stroke or another form of brain injury that affected their ability to process numerical information, or be a carer of such participant. Participants had to have sufficient command of the English language to be involved in a qualitative interview (even if this may be carried out with visual or other aids) and to provide informed consent. Acalculia sub-type was not diagnosed, given that there are currently no assessments to reliably do this. Acalculic symptoms were self-reported, and we asked for examples of difficulties in a pre-interview session. No participant was excluded following this pre-interview session.

Table 1. Brain-injury and Stroke Survivors Participant Information.

Participant ID	Gender	Age	TPO	Profession pre-injury	Carer interviewed?	Carer's relationship
1	Male	64	4	Math teacher	N	N/A
2	Female	69	5	Chief Executive	Y	Partner
3	Female	66	2.5	Data Analyst	Y	Partner
4	Female	32	10	University Student	Y	Parent
5	Female	56	4	Solicitor	Y	Partner
6	Female	53	3	Regulatory and Clinical Scientist	Y	Partner
7	Male	71	2	Web marketing	Y	Partner
8	Male	60	6	Musician	N	N/A
9	Female	37	13	Bar tender	N	N/A
10	Female	47	5	Medication dispenser and team manager	Y	Partner
11	Female	62	27	Nurse	N	N/A
12	Female	74	8	Language teacher	N	N/A
13	Male	52	4	Social work and team manager	N	N/A
14	Male	70	5	Music teacher	N	N/A
15	Male	57	4	Heating engineer	N	N/A
16	Male	68	10	Operation manager	N	N/A

TPO: Time post onset

Procedures

Once participants responded to the advert, they were sent an information sheet and consent form for the study. Depending on participants' preference, it was sent either via the post or in electronic format. Initially, in-person interviews were planned. However, the online interview format was required by social distancing restrictions at the commencement of the Covid-19 pandemic in 2020. Once signed forms were returned, an initial short pre-interview meeting was arranged online via the Whereby platform (https://whereby.com). The platform was chosen as it does not require a separate app (which may make it difficult for some patients to access) and it complies with EU data protection laws, unlike many other platforms. The purpose of this pre-interview session was three-fold. First, it allowed us to ensure that the participant could manage the technology, and if any assistance were needed, we could arrange this ahead of the interview. Secondly, we used it as an opportunity to familiarize the participant with the interviewer, and create rapport; thirdly, as fatigue is a common side-effect following a stroke or another form of brain injury (Belmont et al., 2006), we wanted to minimize the cognitive load on participants during the actual interview. Overcoming the technical difficulties and initial introduction, and taking consent and any background information prior to the main interview session, meant participants were fresh and alert for the full duration of the interview. We would recommend this strategy for use in future studies involving this population. In addition, to help participants prepare for the interview (and again reduce stress and cognitive load), we offered participants the opportunity to receive the interview schedule ahead of the interview, explaining that the questions were guidelines, and the conversation may deviate. Most participants expressed a wish to have the written version of the questions, again a practice we would recommend to those carrying out similar research with stroke survivors in the future.

On the day of the interview, participants were asked to confirm that they consented to participate, and then started the interview. As interviews were conducted online during the Covid-19 pandemic, both participants (often with the carer present) and the researcher were speaking from their own homes.

Materials

Both the information sheet and consent form were provided in two formats- a standard format for healthy adults, and a format that is designed to be easier to read and understand for those with aphasia. These were designed by the second author, based on principles developed by Palmer and Jayes (2020). See Figure S1 in the supplementary material for sample items.

The interview questions were developed in collaboration with two stroke survivors who initiated, and have been closely involved with, the project. Questions were further informed by neuropsychological case studies of acalculia, where symptoms were previously reported (e.g., Granà et al., 2006; McCloskey et al., 1986), and by more recent assessments of acalculic symptoms in everyday life (Semenza et al., 2014; Toffano et al., 2021; Villain et al., 2015).

Interviews were conducted by the third author, who also piloted the topic guide with one participant. No changes were made as a result of this pilot and the participant's data were included in the final data set. Interviews started with general questions about the effect of the stroke/ injury in general, and then focused on aspects of numerical difficulties. The list of questions was used flexibly in interview sessions to stimulate discussion, and included questions about specific tasks (e.g., managing money or passwords), feeling about the difficulties with numbers ("How do you feel about your difficulties with xxx?"), and any compensatory strategies that participants developed to overcome their difficulties. Carer participants were asked similar questions to stroke and other forms of brain injury survivor participants; for example, if the survivor was asked how the stroke had affected their life, the carer was asked how it impacted their own life too. Finally, participants were asked if there was anything they would like to add, to ensure no crucial information was overlooked. The digital recorder was then turned off, and participants were thanked for their participation.

Data analysis

The video and audio-taped interviews were transcribed by the third author using Otter (https://otter.ai) and then the first, second, third, sixth and seventh authors manually corrected the transcriptions, adding gestures and comments where relevant. The resulting transcripts were offered to participants to see, and those who wished to do so, obtained their transcripts to review. Data were then analysed by all the authors, through both inductive and deductive descriptive thematic analysis (Braun & Clarke, 2006) using NVivo12 Qualitative Data Analysis Software (QSR International, 2019). Inductive thematic analysis was chosen as it enables rich themes to emerge from the data, and these are linked strongly to the information provided by participants (Patton, 1990). However, deductive analysis was also employed, as the aims and objectives of the study helped to guide the analysis.

Braun and Clarke's (2006) six stages (familiarization, coding, generating themes, reviewing themes, defining and naming themes, and writing up) were followed. These stages were followed by reading through the interviews and identifying words and concepts that appeared interesting within the data, developing these into themes, reviewing these between the authors, and picking out prominent themes based on their frequency. Transcripts were read at least twice before analysis- once following the correction of transcription and the annotation of gestures/things the participants showed on the screen, and then again by the first author, before coding. During both readings, points of interest were noted. Line-by-line coding took place on a third read. Lastly, these codes were organized into themes with a more general "umbrella" style meaning. The coding and themes were discussed and agreed upon by all the authors, including our PCPI (Patient, Carer and Public Involvement) partners. We did not return to participants to discuss the resultant themes, but those who asked to receive a copy of the results were sent a link to the preprint version of the manuscript.

Results

Three main themes were constructed from the data: Awareness and Diagnosis; Emotional and Practical Impact (independence); Support, Coping Strategies and Self-training.

Theme 1: Awareness and diagnosis

Participants emphasized that concerns about language and mobility took precedence in the period immediately post brain-injury, and that they only became aware of their specific difficulties with numbers later in their recovery. This period of lack of awareness of their acalculia varied between individuals from a few weeks to a couple of years, depending on when they first had to use numbers.

> So since I had [my stroke], my problems were in order was firstly, to speak first. And then my reading and writing followed, and for the first year, I didn't touch maths at all … . [P1]

> It didn't occur to me that numbers were a problem until I went back to work. [P12]

As illustrated above, the level of participants' awareness of acalculia appeared to depend on how they used numbers in their daily lives. Participants' awareness was also often directly influenced by how much support they received from their carers:

> Well, for for a long time, I thought that it was normal … .I didn't notice anything because I think [Carer} did everything for me really. Um, but so like, the bank we've got [bank name] and there's no erm shops, it's only erm phone and erm they said, oh have the third letter and and you know, six digits and and I thought oh … I just couldn't do it. … .that's the first time that I thought actually maybe numbers is are are a bit different now but I just think because you [note: C10] did everything for me really, that I didn't really notice [P10]

Both stroke and other forms of brain injury survivors and their carers reported that patients, carers and professionals all lack awareness and understanding of acalculia and of the nature of difficulties using numbers:

> I wasn't aware of a Acalculia. For me it's part of Aphasia. It was jumbled together [P1]

> I forget what you call your thing, it's got a name hasn't it? And I sort of I'd rather sort of assumed it was a bit like a dyslexia with numbers … . [C3]

> But when I started seeing the maths at the hospital, I said to the lady, who was in charge of my speech, I said, I've got this biggest problem I can't do maths, and I can't understand it, because it to me, it's it's natural to be able to do this. And she said that, possibly that may be part of the speech thing … [P7]

> But … majority of people they have no idea that numbers could be affected by, it's just shocking … You know, I'm saying I have dyscalculia [note: acalculia]. I have I cannot deal with numbers "but you're fine with numbers". No, I'm not fine with numbers. It's a real struggle. And it's lack of understanding … [P9]

This lack of awareness often contributed to lack of support for acalculia, which we discuss in Theme 3.

Theme 2: Emotional and practical impact (Independence)

Participants reported that acalculia had both emotional and practical impacts on their daily lives. The emotional impact of acalculia differed between participants, depending on their relationships with maths before their injury. For example, some participants explained that maths was never their strength: "It [maths] was never my my strong point. I prefer the languages" [P12]; "cause my maths was never a good thing anyway" [P13]. For these participants, the emotional impact of acalculia appeared to be mild.

However, when numbers were perceived by participants and carers to be central to a participant's identity, acalculia led to particularly strong feelings of frustration and distress. For example, participant P7's carer reported that "he could always sort of boast and say I'm good with numbers … ." [C7]. Participant P7 explained the negative impact of acalculia on his ability to engage in favourite leisure activities:

> To me, the numbers you know the biggest problem … . I get very upset. and I just feel that the … . If I had more help than that, that would be better … . I like I would like to be able to do, I don't particularly want to do physics again, but I'd like my, you know, the Sudoku and (unclear speech). I wish. I wish I could do it again. [P7]

For some, emotional reactions were in response to specific situations, which resulted in feelings of vulnerability, shame and/or embarrassment, and even reduced confidence and anger:

> Yeah, um, when I had my after my stroke, I took a girlfriend out for supper. And I paid the bill because it was her birthday. And the waitress ran down the road and said, you've given me about 50 pounds too much. Because I'd got no I just had to I just had another didn't know what the bill was … yeah, I felt vulnerable … [P2]

> [Note: The O/T suggested going to the local shop to practice money and number skills] … and I thought that was the last straw. I thought no, in the shop. Everyone in the village is … going to know that I've got a problem with numbers. And I didn't want I definitely don't want to people just to eww I just didn't like it at all. [P2]

However, for other participants, the impact on their confidence and well-being was more general and not specific to any one event:

> Written question: How do these problems make you feel?
>
> Written response: I feel dumb, embarrassed, and frustrated. [P4]
>
> [note: problems with numbers affect her] A great deal. Certainly with confidence, um, I think she realizes that this is a deficit. And it's a problem that she, she, never had before the accident. She was quite capable on all kinds of numerical and she was doing research at the University … . it's been a big loss to her. [C4]
>
> P10: I'll get angry and frustrated and sometimes I say oh god I'm rubbish … I feel, I'm sorry. I feel sad.
>
> C10: Sometimes you say you're "thick". [P10 & C10]

Some participants reported feeling less emotionally affected over time, as they either made adjustment in their life, or simply got used to their limitations:

> Interviewer How do you feel about the numbers difficulties in general?
>
> P11: ammm … . used to it used to it. [P11]

Other than the emotional impact, acalculia impacted negatively on almost every aspect of daily life. Perhaps the most obvious numerical information in life is within financial management. Some participants reported difficulties in understanding how to pay a bill with the cash they had available. Some participants, to avoid the embarrassment of giving the wrong money, reported using other methods of payment:

> So I've learned this from a lot of people who are … They will, they will buy … they will pay card or they will pay by big, big notes, like 50 pounds [to avoid having to count money/ admit they are not sure how much is needed]. [P1]

But for some, using a card did not make things easier, as difficulties using numbers often affected their ability to remember numerical pin numbers:

> I couldn't work out the numbers I just completely forgotten all the numbers … [P12]

Another common everyday impact of acalculia reported by participants was communicating about or managing time. For some, this related to difficulties understanding, communicating or remembering dates: "I don't know what the date is tomorrow" [P5]. But difficulties with telling or understanding times were more prevalent. In some cases, the difficulties were in processing the spoken numbers:

> again in the early days, it's quite hard to get to "ten to two" or "five minutes past four" or something like that. And even then, if, if the counting is the timing is "20–10" rather than "9:40" is easier doing 9:40 then "20–10" [P8]

> P10: like even with time, if [C10] tells me the time, I need to at least, say that again.
>
> C10: Yeah, repeat it [P10 and C10]

For others the problems were more profound, in that they did not involve difficulties in processing the numbers, but rather instead involved having to relearn how to tell/read the time:

> Time was a disaster. I had to teach myself to tell the time. [P1]
>
> … I've got no concept of judging what what numbers are, so that it's it's almost like Groundhog Day, you going over the same things again, and again, and again. But I've got no, I've got no idea about, I can tell the time [note: when it is on digital clock]. But we've got a different clock in our kitchen [Note: an analogue one]. I can't tell the time. I can't tell the time with that. Because I have to look at my watch to tell the time … [P2]

These problems extended to understanding the concept of time, not just the numerical information associated with it. For example, one participant reported not being able to understand how long half an hour was. Related to difficulties managing time, participants reported impacts on travelling, and the ability to travel independently:

> Well, I think if you had to go something on your own, just say for example, if you decided to go into London on the train and they said over the speakers This train has now been cancelled. You now have to go to platform C and the train will leave at 2.40. That might blow your brain [C10].

Numerical and time information also affected the ability of individuals to use and understand travel timetables. Participant P1 explained the nature of these difficulties:

> Firstly, you have to know how to work how, how to tell the time and it's full of digits. And one of the things you will find with people with a stroke, your ability to remember numbers, digits are is very difficult [P1]

Difficulties with numerical information also affected the processing of addresses. For example,

> I know [note: the address] It's seven [street name]. I know it's [city area]. Yeah. I've been practicing these things. Yeah, … I've re-learnt my address. I wouldn't I would be find it a challenge to say, my postcode, it's XX is XX, XX [note: mostly the letters in the post code] something. I've got no idea what the numbers are, but I'm going to relearn them. I'm going to re relearn. [P2]

Even when participants know their postcode, they often find they swap the digits, for example,

> Ah, yes, my postcode is [Note: saying post-code], but if I've got to write that, that will take time (.) Six it's a six that is the problem, I'm sure of it. Six and seven and 6 and 5, and six again. [P8]

A further reported impact of acalculia was on telephone communication. Using telephone numbers was problematic for some participants. For our youngest participant [P4], this was reported as the worst impact of her acalculia:

> Interviewer: If you would need to tell me what's the most difficult to do with numbers in everyday life? What would it be?
>
> P4: phone number? [looking at her carer] Yes. Oh. [P4]

Participants reported that they had difficulties dialling telephone numbers and writing them down or typing them. Difficulties extended to taking or providing or receiving numbers over the phone- for example, appointment times, or other codes or numbers, which are often needed in our digital age:

> I can easily, dial the wrong number. Yeah, I can easily dial the wrong number, but I've got my iPhone and I just think that an iPhone is a blessing. A blessing because I can look it up. [P2]
>
> Almost certainly every telephone number she wrote down was yes, it would have a wrong digit in it. Well, and that still exists today. She does transpose digits. So for [p2], these days, if she wants to dial a number quite often she'll start off getting the wrong number. Or if she's using a password that involves numbers is quite likely to also be wrong. [C2]

Using passwords in the digital age posed a specific challenge. Even if no digits are used in a password, individuals are often required to provide characters based on their order location in the word. This is very difficult for patients with acalculia to do. For example, participants reported difficulties accessing passwords for banking or work purposes:

> I gave up. I gave up with with internet banking. I couldn't couldn't work out what was the third letter thing and couldn't get in it to start with [P12]

Difficulties with passwords also proved a problem at work:

> For example, the other thing was at work. You have to change your password for your computer every month. So it was that was too much for me to handle [P13]

Another common every-day impact included activities related to cooking, such as managing weights of ingredients, cooking times, or understanding the meaning of measurements or quantities

> … making macaroni cheese, for example. And I was having to get my husband to help. And I thought, well, how much flour do I put in? … . well, I wasn't sure whether it was half a pint or a pint of milk. And whether it was three ounces of four ounces of flour, it didn't seem to matter. Well, I mean, it would matter obviously, to get the right quantity [P12]
>
> Microwave cooking times are a jumble with numbers. Okay? [P15]

As in previous themes, acalculia had a particularly negative impact if the activity was central to the identity of the participant before the stroke and other forms of brain injury:

> Well it [note: acalculia] affects my whole life because I used to do a lot of cooking (1.5). I've made wedding cakes, catered, you know all sorts of things, you know. Every, you know every family occasion I would be be … do all the catering and one thing another. So I've lost the ability to judge what times people the cooking takes the weight and measures ounces and pounds. [P2]

Some participants reported difficulties in understanding the numerical information in the news, which was common during the Covid pandemic:

> We did the government every day. listened it every day. And erm like the charts, it was alright. But if they said like the deaths are "dededede", [Carer], I would say, can you tell me again, because I just couldn't grasp it. [P10]

Importantly, in some cases, acalculia impacted the participants' ability to take their medication, putting them at risk, or making them reliant on others:

> if they change the medication and I'd have to learn it(.), I'd have to relearn it. … but(.) I know that I take full tablets every morning. Um, I know that I need to go to the doctor to change that medication. Usually [C2] comes with me. Yeah, so no I have a problem with the medication. I'm totally relying on the pharmacist that they will check the dose. I'm I'm totally relying on the pharmacist that they will get it right [P2]

From the carer perspective, medication compliance was a great worry for some:

> I think at the beginning, he it was, again, I, I didn't realize - it was something he'd always done. And then suddenly, he gets a monthly prescription from [pharmacy]. And he was in the middle saying I've run out. And I was thinking, this can't be right. He must be getting it wrong. And that is when I decided that I must, you know, help him. … And … it's difficult for people that live on their own, you know, and I suppose it could lead to really serious problems if you overdose. [C7]

Ultimately, it was clear that collectively, number difficulties impacted the patients' independence and affected their ability to participate in social, family, and work roles they had inhabited pre-morbidly.

> I depend on my parents for handling my money and most other things dealing with numbers. [P4]

> for 30 years that [P6] and I've been together, [P6] was in charge of all the money. So for 30 years, she made money, she invested money, she paid the bills at restaurants, she paid the utilities, she did everything. I didn't touch any money. And after her stroke, after your stroke, we said, okay, it's my turn to be that person. So you haven't You haven't had to do any, you haven't had to do any transactions for better or for worse, [C6]

> mmmm … I didn't understand what they was talking about [.] and then [.] I had to let [name of wife] pay for everything [P16]

Theme 3: Support, coping strategies and self-training

Both participants and their carers repeatedly referred to the lack of awareness of, and treatment for, acalculia by all professionals they came across. This appeared to be related to an absence of pre-registration training in acalculia:

> 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. [P1]

> And I went to see the girl [Note: Speech and Language Therapist] and when I saw her, I said to her look, you know, I my reading isn't perfect. I accept that, we could do things like that. But the real problem is my maths. And she, to certain extent, she didn't know what to do. [P7]

In the absence of support from healthcare professionals, participants and carers also reported not knowing where to seek help:

> And I think if there was one thing I would like to do around numbers, I wish there was someone that we could consult on helping [P4], relearn math skills also relearn numerical skill. But I didn't even know where I would begin to look for those types of services even if they are even available. [C4]

This contrasted markedly with the diagnosis of, and support given for equally prevalent conditions such as aphasia, which most participants praised:

> Ask them [note: therapist] about your punctuation or reading. They will give you clues. They will give you worksheets. They can suggest software. But numbers, as a language therapists. That's not a part of their training. They didn't know. [P1]

> I've had I've had loads of apps for for words. Nothing on numbers [P7]

Participants often suggested that support for acalculia should start early, even though they often prioritized support for mobility and language difficulties early in their recovery (as indicated above).

> on reflection, I should have re-learnt how to do numbers at exactly the same time, as I learnt how to read. [P2]

> Interviewer At what moment do you think it would have been the best time to start working with the number area?

> P9: As soon as as soon as possible? As soon as possible? Because, yeah, you know, as soon as, as soon as I'm able to walk talk feed myself, get straightaway on the numbers. [P9]

Faced with a lack of support, some participants devised their own coping strategies. A common strategy for dealing with numbers, particularly in the early days of recovery, was to use fingers to count and to calculate:

> Yeah, definitely fingers [note: for counting]. I love my fingers. If I lost a finger, I would just lose so much. Yeah, the fingers are great. [P2]

> C6: Then you write with your finger, you do the calculation to do 100 and then you say the answer 1,0,0: 100. So the strategy is using your finger to do that,
>
> *P6: Yeah* [P6 and C6]

Some participants also mentioned using technology, such as their mobile "phone or calculators to help with calculations":

> I think I always have either my phone or a calculator because I have, I would check because I have, I have a lot of numbers [P13]

Some participants reported avoiding calculation at any cost, but using a calculator if absolutely necessary:

> I usually give up, I used to think "it doesn't really matter". I don't need to know that and walk away from it. But I probably if I needed to do it, I do it on a calculator or something. [P3]

Others identified useful apps to support them in using numbers:

> No one has helped me with coping strategies. I do use an app (Tip Calculator) for calculating tips in restaurants. [P4]

Some participants expressed a "wish list" for technological support for example:

> Things like predictive texts are very good. If I could do predictive numbers that would be brilliant, but I can't [P2]

There were also strategies for specific domains. For example, participants reported that relying on others was a common strategy for dealing with money management. For example:

> Well, my friends, we've gone out a few few times to different restaurants. But I normally I used to pay cash and then I say there was like, five and split it. But I wait till the end and then say oh how much (laughs)? [P10]

To deal with understanding and managing time, participants mentioned using alarms (often set up by their carer):

> But like I said, we have got a backup. We've got an alarm on her phone, which goes off to remind her to take her pills. [C10]

Participants reported using specific equipment to help them to deal with quantities when cooking. For example, participants mentioned using measuring cups/spoons:

> One thing that [P2] did do when we're when we were at shopping, we were in a shopping center somewhere, [P2] bought self new measuring cups.… . And so she uses those meticulously to make things like porridge. And yeah, so, yeah, she knows you have one measure of this or one cup of that, and she's found appropriate measures to some of the everyday tasks that she uses. [C2]

As well as coping strategies, some participants developed self-training programmes:

> So I said, right, help me. I need help. "Sorry. No, I can't do it." So if I had to learn my maths, I had to, I had to learn maths myself. Well, luckily, being a math teacher, I had help for myself . . . . I started to write a list of skills. So for example, I started right, I need to do addition, and then subtraction, and then multiplication, and then division, and then telling the time and . . . . So I started looking about dyscalculia. And I recognize the similarities. They're different. But the list was quite close. So when I started the list for skills, I start there. And I thought, right, I can do that tic, I can oh I can't do that. No, I can't do that. I can't do that. So I recognized the similarities of the things . . . . Having said that, eventually, I ditched my list of dyscalculia, because it was not exactly the same. but the skills are the same. [P1]

In other words, a participant who had experience of teaching maths was able to use existing knowledge and skills to support their own development/programme. Others have reported simpler strategies:

> I think that what's been helpful with you is repetition and drilling, repetition and drilling of the of, of mathematics and especially numbers that are employed in activities of daily living. [C6]

> C8 (having been called in by C8 for this explanation): Yes. Well, we quite late on in the speech therapy, I realized that he's struggling with his numbers quite a bit. And I was I was aware that it could get frustrating because he used to do our accounts and everything. So I sort of I think I found some things online, I just thought about it and worked out which of the numbers he had troubles with. And I just used to write out a load of numbers basic and get them to read them to me. And then I remembered, as we asked [SLT], in one of the session whether or not she had any material and she just basically said, "well, what you're doing is fine. Just keep on doing what you're doing. You're thinking of the right things." So I used to make the more complicated and get you know longer digits.

> *P8: Yeah* [P8 and C8]

Discussion

The current study explored the impact of acalculia on the everyday lives of 23 participants: 16 stroke or brain-injury survivors and 7 carers, using semi-structured interviews conducted over web-conferencing software during the Covid-19 pandemic lockdown period. Over 15 h of interview data were analysed using thematic analysis, to generate three main themes in the data: Awareness and Diagnosis; Emotional and Practical Impact; Support, Coping Strategies and Independence.

Awareness and diagnosis

Since the introduction of the Triple-Code Model (TCM) by Dehaene (1992), there has been considerable progress in the theoretical understanding of how numerical information is learned, and processed in the brain (Siemann & Petermann, 2018). This is evident by the approximately 2500 citations of this seminal paper since its publication. However, despite these theoretical advances, it is clear from our data that this knowledge has not been translated into clinical practice. All our participants reported that numerical skills were not assessed, and that acalculia was not officially diagnosed by any of the many and highly skilled professionals they had met during their recovery process. Furthermore, even when the acalculic participant (or their carer) became aware of their acalculia (often much later in the recovery) and requested support for their difficulties with numbers, many professionals were not aware of the condition, and were unable to provide support or recommend procedure for self-practice.

Lack of awareness and attention to numerical difficulties among stroke and other forms of brain injury survivors likely reflects a wider trend in western societies, where numerical skills are considered less important than verbal or literacy skills. This is reflected in the fact that the level of numeracy skills in the UK is generally low (National Numeracy, 2019), even among highly educated individuals (Lipkus et al., 2001) and health professionals (Estrada et al., 1999; Sheridan & Pignone, 2002). Poor attitudes towards numerical skills are also seen in education and the developmental literature, where dyscalculia has received significantly less attention compared to dyslexia, leaving educators helpless in supporting children with their numerical difficulties (Sezer & Akın, 2011).

Remedies to this lack of awareness are likely to require improvements in scientific understanding and in clinical training of health professionals. First, there is a need to develop and disseminate suitable assessments for numerical difficulties, to be used in post-stroke and other forms of brain injury care pathways. At the same time, introducing the concept of acalculia in the training of health professionals, and making patients aware that such difficulties can arise, will encourage both clinicians and patients and their carers to work together to seek and share potential support and where available, solutions (e.g., as described in Theme 3).

Emotional and practical impact (independence)

As previously described by Kowsun (2008), some of the participants in the study reported "never being good at maths", while for others, their mathematical skills were a core part of their identity. Participants' knowledge and experience of numerical information prior to their injury had a direct influence on their emotional response to their difficulties with numbers. When numerical competence was central to their identity, the emotional impact on their mood and confidence was overwhelming, while if their expectations of being able to use numbers were low, participants were generally less troubled by their difficulties. The emotional impact of a disability on core identity has previously been reported, for example, among women with brain injury (Stewart, 2013) and in other conditions such as Multiple Sclerosis (Heward et al., 2011). The impact has not been specifically considered with regards to acalculia. As maths skills have been socially attached to other stigmas, such as being the remit of “mad scientists”, or “nerdy” boys (Epstein et al., 2010), it is logical that those who strongly identified themselves as “good at maths” may have developed this to be part of their social identity (or at least their professional identity), and as a result may experience stronger emotional impact upon losing these skills. Future studies could explore to what extent mathematical skills do form part of a person’s social identity, before and after brain injury.

For most other participants, the emotional impact of acalculia was associated with their experiences post injury. Having experienced negative feedback from others, and/or losing their independence, made many participants angry, sad and/or ashamed. Feelings such as shame or anxiety about dependence as a result of cognitive disabilities have recently been reported common among those with aphasia (Morris et al., 2017), however, there is a lack of data about their prevalence or impact among those who experience acalculic symptoms.

Empowering individuals by providing official recognition of their condition could have a positive impact on participants’ confidence and self-esteem, as previously reported in other late-diagnosed conditions such as autism (Leedham et al., 2020). Interventions designed to support acalculic symptoms could not only improve numerical skills, but also help with the emotional impact of acalculia, as has been observed in other cognitive interventions such as those for healthy older adults (Nouchi et al., 2019) or for those with mild cognitive impairments (Reynolds et al., 2020).

The practical impact of acalculia reported in our findings was wide-ranging, and could be divided into three broad categories, which generally correspond to the three theoretical nodes described by the Triple Code Model (TCM; Dehaene et al., 1999). One common problem reported by participants was communicating numbers in different situations, for example giving their phone number, saying their date of birth. Issues around communication of number words or number names (retrieval and comprehension) could be grouped under the “auditory verbal word form” unit of the TCM. While this is often considered a “surface” (linguistic) form of acalculia, the impact on participants’ independence and quality of life was profound; our data suggest it prevented them from being able to freely travel, make appointments, or use passwords.

The second type of problem reported by participants involved the Visual Arabic form of digits (3,8,11), where participants reported being unable to process digits either on a clock, on price tags/ bills, on train and bus timetables, or to produce digits in the correct order (e.g., writing down “phone numbers”). Several neuropsychological cases in the past have reported visuo-spatial disruptions such as digit swapping, or difficulties transcoding or processing digits (e.g., Cohen & Dehaene, 1991; Deloche & Seron, 1982), but the practical impact on participants’ lives has rarely been considered. Again, our data reveal the degree of frustration experienced by participants, as this impacted their ability to manage their money and to deal with numerical information, which is prevalent in all aspects of life.

Lastly, a few of our participants reported deficits that can be attributed to the third code in the TCM – the analogue magnitude representation, or perhaps, the "core unit" of understudying quantity information. Deficits associated with this unit of the TCM prevented participants from understating quantities such as temperature (is it hot or cold?) and other measurements, including their medications (quantities and frequencies). These cases were less common in our sample (and are likely less common in general), but the impact of these acalculic symptoms should certainly not be overlooked. Even if treatments for these symptoms are difficult to develop, compensatory strategies to support patients and their carers should be considered.

Overall, while it is reassuring to see that the practical impacts identified by our participants fall within well established frameworks of mathematical cognition, it is disappointing to see that there still remains a gap in translational research: these theoretical insights have not been translated into practical assessments and/or interventions. In particular, when designing assessments and interventions, it should be considered that similar symptoms (e.g., the inability to manage medication) could result from different underlying difficulties (e.g., the inability to read the digits on prescriptions, or the inability to understand the meaning of these digits), and hence may be treated differently.

Importantly, the collective practical and emotional impacts of acalculia resulted in substantial impact on participants' independence and quality of life. Acalculia left some unable to return to work, and left many unable to live independently, manage their finances, medications or other everyday activities, and as such left them vulnerable. We are aware of no previous study that has investigated the costs of not diagnosing or treating acalculia, but data from our study suggest these could be significant.

Support, coping strategies and self-training

Many of the participants in the study pointed to the stark contrast between the (often excellent) support they had received for other post-injury difficulties, such as their aphasia or mobility difficulties, and the complete absence of support for their difficulties with numbers. Indeed, numerical difficulties are not currently assessed or diagnosed, leading to a lack of awareness of the condition, and in turn absence of support and treatments.

The lack of support from occupational therapists (OTs) and speech and language therapists (SLTs) was particularly surprising, given the enormous impact reported by participants on their everyday lives, and the often verbal nature of their problems (difficulties with correctly producing number names/

processing number names). While interventions for core numerical difficulties such as understanding of magnitudes are still to be developed and tested, interventions for processing number words could be based on existing interventional approaches involving the training of limited sets of vocabulary. Several reviews and meta-analyses have identified that training words in anomic aphasia results in improved retrieval of these words (but generally does not extend to untrained vocabulary, which is less problematic in this case) (Wisenburn & Mahoney, 2009). More recent work has identified some specific effective components of these interventions, such as presenting written words along with the spoken form (Sze et al., 2021). This approach could easily be implemented within number–word training interventions.

Faced with this lack of support, some participants reported developing their own coping strategies and self- training programmes. Coping strategies included the use of technology where this was available (apps/ calculators), as well as simpler strategies such as using fingers for counting and calculating. The link between fingers and numerical abilities in children (Crollen & Noël, 2015) and in neuropsychological cases (e.g., Gestman syndrome, Mayer et al., 1999) is well documented. It is therefore interesting that participants discovered this intuitively, and found it helpful. This finding is useful, as innately it may seem childish to encourage adults to use their fingers for counting, but our data suggest that it is not only helpful, but more importantly acceptable to many patients. One previous study with a 22-year-old female with post-stroke acalculia explored the behavioural and brain-volume changes following a tactile enumeration intervention (Cohen et al., 2018). Results revealed both performance improvement and enhancement of grey-matter density in the right occipital region. Combining this finding with our findings, suggests that finger-based interventions for acalculia are likely to not only be easy to deliver and effective, but are also acceptable as a strategy for adults.

Other embodied strategies for interventions should also be considered, based on the findings that mathematical performance can be boosted by congruent action. For example, walking to the right and left, can boost performance counting (Lugli et al., 2013) and addition and subtraction, respectively (Anelli et al., 2014). This is possibly because it is equivalent to walking on a virtual number line, and hence is congruent with the cognitive process of counting or calculating. Such insights can support innovative interventions, involving Virtual Reality (VR) environments, which will reduce the social anxiety of performing poorly in public, reduce the risk of making costly mistakes (e.g., losing money) and potentially improve cognitive performance.

Some participants and their carers also developed more elaborate self- training systems, which involved self-initiated work sheets, and intense repetition strategies. Such intense training of calculations has been found to be effective only for some patients (Claros-Salinas et al., 2014), but this could be due to the lack of personalization of the training, or due to performance levels pre-injury (which is often not known). Overall, more evidence and research is required to understand how, and for whom, such interventions could be useful.

Conclusion

Our study is the first to extensively investigate the emotional and practical impacts of acalculia on a varied sample (age, gender, profession, geographical location etc.) of stroke and other forms of brain injury survivors and their carers. Results indicated that the impact on their everyday lives was extensive, and that diagnosis and support for the condition is currently non-existent and urgently needed, and should be prioritized by both the NHS and Stroke Association, following their current priorities for stroke rehabilitation (NHS, 2019; Stroke Association, 2021), and these guidelines should be extended for other brain-injury survivors. In order to effectively support acalculic patients and their carers, several things need to happen simultaneously. Increasing awareness among patients and professionals would encourage them to seek help and push for new diagnostic tools and interventions. This could be achieved by introducing the condition of acalculia during the training of rehabilitation professions such as occupational therapists and speech and language therapists and by providing patients and their carers with information about the condition. There is also an urgent need to develop and integrate acalculia assessment into patient care pathways, and to invest in research on the effectiveness of interventions. Such interventions may include simple strategies such as using fingers for counting and for simple calculation, as well as more sophisticated technical support such as apps for specific functions, training programmes and virtual-reality environments to enable embodied and safe opportunities for assessments and interventions.

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