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A qualitative study investigating the views of stroke survivors and their family members on discussing post-stroke cognitive trajectories

Georgina Hobden ^a, Eugene Yee Hing Tang^b and Nele Demeyere ^c

^aDepartment of Experimental Psychology, University of Oxford, Oxford, UK; ^bPopulation Health Sciences Institute, Newcastle University, Newcastle, UK; ^cNuffield Department of Clinical Neurosciences, University of Oxford, Oxford, UK

ABSTRACT

Cognitive impairment is common early after stroke but trajectories over the long term are variable. Some stroke survivors make a full recovery, while others retain a stable impairment or decline. This study explored the perceived advantages and disadvantages of discussing potential cognitive trajectories with stroke survivors and their family members. Stroke survivors at least six-months post-stroke were purposively sampled from an existing pool of research volunteers recruited originally for the OCS-Recovery study. They were invited, alongside a family member, to participate in a semi-structured interview. Interviews were audio recorded, transcribed, and analyzed using reflexive thematic analysis. Twenty-six stroke survivors and eleven family members participated. We identified one overarching theme and three related subthemes. The overarching theme was: One size does not fit all. The subthemes were: (1) Hearing about potential cognitive trajectories helps to develop realistic expectations; (2) Discussions about cognitive trajectories may be motivating; (3) Cognitive decline and post-stroke dementia discussions may be anxiety-provoking and depressing. Healthcare professionals should adopt a person-centred approach to sharing information about post-stroke cognitive trajectories. Discussions should be tailored to individual needs and preferences, with dementia-related topics in particular addressed with the utmost selectivity and sensitivity.

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Introduction

Cognitive impairment affects a large proportion of people with stroke in the early stages (range: 48–98.4%) (Demeyere et al., 2016; Hurford et al., 2013;

CONTACT Georgina Hobden  Georgina.hobden@psy.ox.ac.uk  Department of Experimental, Anna Watts Building, Woodstock Road, Oxford, OX2 6GG, UK

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Lesniak et al., 2008; Milosevich et al., 2023; Nijse et al., 2017; Turunen et al., 2018), with exact prevalence estimates varying based on the characteristics of the included cohort and measures used (e.g., Bath et al., 2017; Hurford et al., 2013). Over the longer term, post-stroke cognitive functioning follows highly complex and heterogeneous trajectories (del Ser et al., 2005; Demeyere et al., 2019; Kusec et al., 2023; Tang et al., 2018). A proportion of stroke survivors recover from early cognitive impairment (Demeyere et al., 2019; Kusec et al., 2023), but approximately half continue to experience cognitive impairment six-months post-stroke (Franklin et al., 2018; Jokinen et al., 2015; Lopes et al., 2021), with some research suggesting an even higher long-term prevalence (Milosevich et al., 2023). Long-term cognitive impairment represents a stable impairment in some cases but, for others, early cognitive impairments become more severe over the months and years after stroke (Demeyere et al., 2019). Furthermore, stroke survivors are at a significantly increased risk of developing vascular and mixed dementia (e.g., Pendlebury & Rothwell, 2019), with a recent systematic review and meta-analysis concluding that approximately 20% of stroke survivors experience clinically defined dementia one-year after stroke (Craig et al., 2022). However, there is currently no reliable way to predict long-term outcomes on an individual level (Tang et al., 2020).

Clinical guidelines recommend screening for cognitive impairment as soon as possible after stroke (Intercollegiate Stroke Working Party, 2023; Quinn et al., 2021), but guidance on what should be done following this assessment is currently not well defined. Informing stroke survivors and their family members about the assessment result is an important first step (Hobden et al., 2023) but it may also be beneficial to discuss possible long-term cognitive trajectories to facilitate future care planning and increase awareness of symptoms to monitor. Nevertheless, before incorporating prognostic discussions routinely into clinical practice, it is critical to explore the potential advantages and disadvantages of sharing this complex and potentially emotive information with stroke survivors and their family members.

A recent systematic review synthesized 28 qualitative studies on sharing information about recovery after acquired brain injury (Burton et al., 2021). Burton et al. found that participants across the studies wanted “the right information at the right time” (p. 9), but this looked different depending on the specific patient group – for example, people with stroke were generally more receptive to prognostic information than those with brain tumours. Nevertheless, providing information about recovery brought challenges for both health-care professionals and patients, and it was important for clinicians to tread carefully to ensure prognostic discussions provided a realistic expectation for the future without extinguishing hope. The need for appropriate training in this area was stressed, with clinicians recognizing the complexity and emotive nature of prognostic discussions. Overall, the review provides valuable insight into recovery-related clinical conversations after brain injury, but only a minority

of the included studies were related to stroke, and none focused on post-stroke cognition specifically.

Homing in on post-stroke cognitive recovery, Cheng et al. (2022) conducted a series of semi-structured interviews with stroke survivors and their caregivers to explore perspectives on sharing prognostic information about aphasia. Caregivers were generally receptive to this information, so long as it enhanced their ability to help their family member in recovery. Nevertheless, whereas non-partners (e.g., children, parents) tended to want both favourable and unfavourable predictions about recovery as early as possible, partners generally expressed a lesser desire for prognostic information, preferring information about maximizing recovery. Using a similar qualitative approach, Tang et al. (2019) explored clinician, stroke survivor, and carer perspectives on using dementia risk prediction tools to inform discussions about post-stroke dementia. Participants noted some potential advantages of discussing post-stroke dementia – for example, to help prepare for the future, to ensure a timely diagnosis, and for reassurance – but there were also disadvantages, including anxiety about a diagnosis and concerns about how such information would impact recovery. These disadvantages are potentially reflected by quantitative data from Ball et al. (2022), who surveyed 60 UK healthcare professionals. Although 57% of participants in this study thought acute stroke patients would benefit from knowing if they were at high risk of dementia, 89% never or rarely discussed dementia with their patients.

The above articles offer valuable insight into perspectives on delivering information about post-stroke cognitive trajectories, but none of them fully capture the complexity of post-stroke cognitive impairment as a problem that affects multiple domains (e.g., language, memory, attention, executive function, number processing, praxis) (Demeyere et al., 2015) and follows varying trajectories (Milosevich et al., 2023; Nys et al., 2005). The aim of this study was therefore to explore the potential advantages and disadvantages of discussing post-stroke cognitive trajectories – encompassing cognitive recovery, stability, decline, and dementia – from the perspective of stroke survivors and their family members. This has important clinical implications in terms of determining whether, to what extent, and how information about post-stroke cognitive trajectories should be shared with stroke survivors and family members in clinical practice.

Methods

Participant sampling

Stroke survivors were purposively selected from a database of participants who had previously taken part in the OCS-Recovery study (NHS REC reference 18/SC/05501) and agreed to be contacted for future research. This pool of research

volunteers included a sample of patients hospitalized for stroke in Oxford (United Kingdom) who were at least 18 years old and able to remain alert for at least 20 minutes at the point of initial recruitment.

For the present study, we purposively sampled participants of different ages and genders, as well as participants with different cognitive profiles and stroke severities. Originally, we recruited family members to the study only in cases where the stroke survivor had a language impairment impacting their ability to express their views during the interviews and preferred their family member to be present. However, we later opened the study to all family members who were happy to contribute their views.

The research team contacted potential participants by telephone and provided them with detailed information about the study. Potential participants were offered the opportunity to ask any questions at this point. Stroke survivors and family members provided informed consent to participate in an audio recorded semi-structured interview, as well as consent to link their previously acquired research data from the OCS-Recovery study to the present interview data (University of Oxford Medical Sciences Interdivisional Research Ethics Committee Approval Reference: R80681/RE001).

Data collection

Semi-structured interviews took place between May 2022 and September 2022. Interviews were conducted by GH, a doctoral student in Psychology who had completed advanced training in qualitative data collection and analysis with the Social Research Association. Interviews were conducted at the participant's home or remotely via telephone, with participants selecting their preferred mode of interviewing. The majority of interviews were conducted individually but stroke survivors were interviewed alongside their family member when preferred. Detailed field notes were made after each interview. Audio recordings of the interviews were transcribed by GH as part of the data familiarisation process using Jeffersonian Lite style (Potter & Hepburn, 2005), with all identifiable personal data removed from the transcripts. The transcripts were password-protected, labelled using unique participant identifiers, and stored on a computer with an encrypted hard drive to protect participant anonymity.

Interviews were structured around a topic guide developed by the research team, based on their clinical expertise and relevant literature, and edited iteratively as interviews progressed. Most questions were open-ended to allow flexible dialogue between the participant(s) and interviewer, with the questioning style adjusted and communication support strategies (e.g., probing) used to support participants with aphasia (Luck & Rose, 2007). Participants were asked questions about their experiences of post-stroke cognitive assessment and perspectives on cognitive trajectory discussions. Given

the richness of the interview data, results of these two questions are presented separately: this article explores stroke survivor and family member perspectives on cognitive trajectory discussions, whilst the article by Hobden et al. (2023) presents experiences of post-stroke cognitive assessment. In the interviews, we defined post-stroke cognitive trajectories as “whether thinking skills – such as memory, language, and attention – improve, remain stable, or get worse”.

Participant demographics and clinical information were retrieved for this study from data collected during the OCS-Recovery study. Clinical information used for this study were stroke severity, assessed by hospital staff during acute inpatient admission using the National Institute of Health Stroke Scale (NIHSS; Brott et al., 1989), and cognitive profile, also assessed acutely by hospital staff using the Oxford Cognitive Screen (OCS; Demeyere et al., 2015).

Data analysis

Interview data were collected and analyzed iteratively using the principles of reflexive thematic analysis (Braun et al., 2019; Braun & Clarke, 2019a). Themes were derived from the data and informed by prior research and expectations based on clinical experience, though the analysis was positioned towards the inductive end of the spectrum. One member of the research team (GH) coded a subset of interview transcripts and developed an initial set of themes and subthemes. Themes/subthemes were clarified, refined or removed as interviews progressed. The research team discussed the themes and subthemes regularly throughout the data collection and analysis process and all members of the team agreed the final theme structure presented below reflected the interview data and met the analytic goal of the study. The research team agreed to stop data collection and analysis based on several factors, including pragmatic constraints (e.g., on time and resources) and whether they believed the analytic goal of the study (to develop a theme structure encapsulating perceived advantages and disadvantages of discussing potential post-stroke cognitive trajectories) had been reached (Braun & Clarke, 2019b). The research team adopted a reflective approach by recognizing and remaining mindful of their professional expertise (GH and ND: cognitive and clinical neuropsychology; EYHT: primary care for stroke) and views, being cautious to limit the extent to which these factors shaped the final presentation of results, though acknowledging that themes were inevitably developed at the intersection of the data, contextual factors, and research team perspectives and viewing the interpretive role of the research team as an asset to the analysis. Computer software (NVivo V.11, Microsoft Word V.16.7 and Microsoft Excel V.16.7) facilitated data management and analysis. The paper presented conforms to the Consolidated Criteria for Reporting Qualitative Studies checklist (Tong et al., 2007).

Table 1. Demographic and clinical characteristics of interview participants (stroke survivors).

Participant identifier	Role	Age	Sex	OCS	NIHSS
SS1	Stroke survivor	63	M	0	0
SS2	Stroke survivor	54	M	2	0
SS3	Stroke survivor	62	F	0	3
SS4	Stroke survivor	78	F	3	3
SS5	Stroke survivor	61	M	4	18
SS6	Stroke survivor	73	F	2	14
SS7	Stroke survivor	77	M	0	6
SS8	Stroke survivor	73	F	1	7
SS9	Stroke survivor	71	M	7	9
SS10	Stroke survivor	81	M	4	5
SS11	Stroke survivor	87	M	4	5
SS12	Stroke survivor	77	M	3	18
SS13	Stroke survivor	74	F	3	12
SS14	Stroke survivor	84	F	9	4
SS15*	Stroke survivor	70	M	2	3
SS16	Stroke survivor	75	M	1	NA
SS17	Stroke survivor	77	M	7	6
SS18	Stroke survivor	75	M	1	NA
SS19	Stroke survivor	81	F	2	1
SS20	Stroke survivor	73	M	6	16
SS21	Stroke survivor	68	M	11	4
SS22	Stroke survivor	80	M	7	3
SS23	Stroke survivor	56	M	1	NA
SS24	Stroke survivor	75	M	9	5
SS25	Stroke survivor	78	F	4	11
SS26	Stroke survivor	69	F	7	12

OCS refers to performance on the Oxford Cognitive Screen during inpatient hospital admission during the acute/subacute stage post-stroke. We present the number of tasks on which participants were categorized as impaired, relative to normative data. The OCS includes a total of twelve tasks. NIHSS refers to participants' stroke severity, recorded during the acute/subacute stage post-stroke and scored using the National Institute of Health Stroke Scale, which ranges from 0 to 42.

*Completed two interview sessions due to technical error. NA = Not available in medical records.

Results

We present the characteristics of the stroke survivors and family members interviewed in the present study in [Tables 1](#) and [2](#), respectively. We interviewed 37 participants, including 26 stroke survivors and 11 family members. Interviews were conducted via telephone in 11 cases and the remaining 17 interviews were conducted in person. The interviews lasted 47 minutes on average (range = 14–119 minutes).

Table 2. Interview participants (family members).

Participant identifier	Role	Relationship
FM1	Family member of SS5	Wife
FM2	Family member of SS6	Husband
FM3	Family member of SS7	Wife
FM4	Family member of SS9	Wife
FM5	Family member (stroke survivor not interviewed)	Daughter
FM6*	Family member of SS15	Wife
FM7	Family member of SS17	Wife
FM8	Family member (stroke survivor not interviewed)	Son
FM9	Family member of SS20	Wife
FM10	Family member of SS22	Wife
FM11	Family member of SS24	Wife

*Completed two interview sessions due to technical error.

We identified one overarching theme from the interviews and three related subthemes pertaining to the potential advantages and disadvantages of discussing potential post-stroke cognitive trajectories with stroke survivors and their family members. The overarching theme was: One size does not fit all. The related subthemes were: (1) Hearing about potential cognitive trajectories helps to develop realistic expectations; (2) Discussions about cognitive trajectories may be motivating; (3) Cognitive decline and post-stroke dementia discussions may be anxiety-provoking and depressing. Key quotes are provided to illustrate these subthemes with participants labelled using their unique participant identifiers (see [Tables 1](#) and [2](#)). Additional quotes are presented in Supplementary Table 1.

One size does not fit all

The interview data suggested information about potential cognitive trajectories may be received very differently by individuals, with person-specific factors (e.g., perspectives on cognitive impairment and dementia) and the timing of information provision having a substantial – and potentially interactive – impact on responses to the information. For example, participants who described themselves as optimistic were generally positive about cognitive trajectory discussions and thought this information was particularly important to provide in the early stages after stroke to enable stroke survivors and their family members to develop realistic expectations for the future. In contrast, some participants who reported a proclivity towards worrying thought that only positive information should be provided, as information about dementia and cognitive decline could be anxiety-provoking, particularly should it be provided in the early stages after stroke. In this sense, although there was substantial overlap in the specific advantages and disadvantages identified, participants seemed to weigh the advantages and disadvantages differently, depending on their individual perspectives. Commonly identified advantages and disadvantages are described by the subthemes below.

Hearing about potential cognitive trajectories helps to develop realistic expectations

Several participants described how they had felt uncertain about how their cognitive functioning would evolve over time and how any cognitive impairments could impact their daily lives. These participants felt that learning about potential cognitive trajectories in the early stages after stroke would have helped them develop realistic expectations for the future, attenuating feelings of uncertainty and accompanying anxiety.

SS20: I think that information is really useful. Either it's motivating, which is sort of a positive scenario, or it makes the patient more realistic about the potential outcomes.

Most participants who spoke about the importance of developing realistic expectations for cognitive recovery experienced cognitive impairment affecting several domains in the early stages after stroke, suggestive of a potentially moderate cognitive impact of stroke (e.g., SS20 and SS5 were impaired on six and four out of the twelve cognitive tasks in the OCS, respectively). However, one stroke survivor with cognitive impairment affecting only one domain, suggesting a potentially milder impact, also thought it would have been helpful to discuss cognitive trajectories, in order to develop realistic expectations. Nevertheless, he stressed the importance of promoting awareness about ongoing cognitive impairment and cognitive decline without generating fear.

SS18: I think it might have been useful for me to have been more aware that [cognitive decline] was a possibility and therefore, possibly if I'd been more aware of it, I would have looked out for it more, you know, when I recovered. [...] I think awareness is the issue, isn't it? Not being totally in the dark about it but not being too frightened about it at the same time. I didn't want to be scared about it. I didn't want to be scared about the future. I wanted to be positive about the future and I wanted to get on with my life.

Being discharged from hospital was seen as a particularly challenging point in the post-stroke recovery period, so many participants believed it would have been ideal for information about potential cognitive trajectories to have been provided beforehand. Indeed, one participant commented on the disorientating experience of leaving hospital without knowing what to expect over the long-term, and he explained that a discussion about cognitive trajectories may have helped to alleviate these uncomfortable feelings of uncertainty.

SS18: It would have been helpful, I think, just to have a little bit more information [about post-stroke cognitive trajectories] and to maybe have had that discussion briefly, just to be aware of – or more aware of – what might be the [...] progression afterwards. I didn't know what to expect coming out. I was out so quickly. I wasn't quite sure how quickly I should be improving, what difference it should have made to my day-to-day living – very little, as it happened. But I didn't have that conversation.

Most participants commented that they had not received any information about cognitive functioning (see also Hobden et al., 2023) or cognitive trajectories in the early stages after stroke and this lack of information had led some of them to generate overly optimistic expectations for future cognitive recovery. In the early stages after stroke, optimism and positivity about cognitive recovery served a useful function by helping participants cope with their – or their family member's – cognitive impairment. However, participants acknowledged the value of having "known facts" (FM1) about cognitive trajectories to temper their expectations and to balance their idealism with realism (Supplementary Table 1 for quote).

Some participants' optimistic expectations and goals for cognitive recovery persisted many months after stroke, as they still had not received information

about cognitive trajectories to temper these expectations. For example, one stroke survivor with severe expressive aphasia, which had persisted six-months after his stroke, still expected that his language abilities would return to pre-stroke levels at some point (Supplementary Table 1 for quote). When describing similar situations where optimistic expectations and goals for cognitive recovery were not met, stroke survivors and their family members identified feelings of disappointment and frustration. They believed discussing cognitive trajectories early after stroke may have helped temper expectations and, in turn, avoid such negative emotional responses when unrealistic expectations were not met (Additional quote in Supplementary Table 1).

SS15: Aphasia – it’s different [...] for every person, I think. I was always very clear that I was going to get much better than I was and I’m not sure I’ve done it at the rate at which I thought, initially.

FM6: Yeah, you thought you’d be all better by now.

Nevertheless, a minority of participants did not agree that information about cognitive trajectories would have helped them develop realistic expectations. Instead, they discussed the importance of providing only “encouraging” (SS25) information that would help stroke survivors and their family members retain hope and optimism for the future. In other words, whereas some participants preferred to temper optimism with factual information, others valued hopefulness over and above realistic expectations.

Discussions about cognitive trajectories may be motivating

In addition to helping develop realistic expectations, several participants described how information about post-stroke cognitive trajectories could be motivating for stroke survivors and their family members. Information about cognitive recovery in particular was seen as potentially beneficial, as participants believed discussing future recovery may help motivate stroke survivors to engage with rehabilitation exercises, which were often perceived as tedious (Supplementary Table 1 for quote).

Some participants felt that discussing cognitive decline and post-stroke dementia would also be motivating for stroke survivors, although this sentiment was less common among participants and there was some discrepancy between opinions. Generally, these differences in opinion seemed to be driven by individual perspectives and outlooks on post-stroke recovery. One stroke survivor, who described himself as “very positive about everything” (SS16), explained that information about post-stroke dementia would have motivated him to reduce his risk of developing it. Similarly, another stroke survivor (SS5) believed that his competitive nature would have compelled him to fight against the possibility of cognitive decline, had this been discussed with him in the early stages after stroke.

SS16: [Information about post-stroke dementia] wouldn't upset me. I'd just say "Right, okay, [...] what do I need to do to try and reduce that risk?"

SS5: If someone had said "Oh, you're going to go down", or "You're going to flatline", I'd have fought against it.

One stroke survivor commented that information about cognitive trajectories would have been neither motivating nor demotivating for him had it been provided in the early stages after stroke, as he believed his personal determination would ensure a positive recovery, regardless of its statistical likelihood. As such, he thought information about post-stroke cognitive trajectories would have served little useful purpose in motivating *him* to recover, but he acknowledged the information may have a motivating impact on stroke survivors less determined than him.

SS16: My mind was made up – I was going to get better. If there'd have been a doctor that was saying "Well, these are all the problems," you know "This is what we can do maybe", then it wouldn't have helped me, but it might have helped some people in my position.

The sentiment that information about cognitive trajectories may be motivating for some but not for others was echoed by participants who highlighted the importance of health professionals adopting an individualized approach when discussing cognitive trajectories. In particular, before providing information about cognitive trajectories, participants felt it was important for health professionals to determine whether or not stroke survivors would be "egged on" (FM8) by this information.

FM8: I think you almost have to determine the person's sort of 'glass half full' versus 'glass half empty' status before you decide what to say and what not to say, don't you? Because if they're the ones that are egged on by it, then yeah, I can absolutely see why [cognitive trajectories are] something to talk about.

Cognitive decline and post-stroke dementia discussions may be anxiety-provoking and depressing

Several participants were concerned that providing information about post-stroke cognitive decline and post-stroke dementia would increase feelings of anxiety and low mood among stroke survivors and their family members. Some of these participants reasoned that stroke survivors have little control over whether their cognition deteriorates, due to the lack of interventions available to prevent post-stroke cognitive decline or dementia. They believed that hearing about post-stroke cognitive decline/dementia, without being able to do anything to prevent it, would accentuate negative emotions (Additional quote in Supplementary Table 1).

SS25: Having a stroke is bad enough without having additional worries piled on, basically. You know, you worry about getting better but if somebody said to you, you

know, you might get an awful lot worse or you might get dementia, you'd feel like giving up.

However, some participants argued that discussing post-stroke cognitive decline and dementia would not have made them “any more worried” (SS7). For one stroke survivor (SS7), his lack of agency and control over post-stroke cognitive decline and dementia in fact buffered him against feelings of anxiety. This stroke survivor and his family member adopted a pragmatic attitude about potential cognitive decline and dementia, acknowledging that feeling anxious or depressed would serve no useful purpose and that living in the present moment was a preferable alternative.

SS7: It's not good being worried about [post-stroke dementia]. If it's going to happen, it's going to happen.

How participants perceived dementia as a condition seemed to be an important factor in determining whether they believed information about post-stroke cognitive decline and dementia would trigger negative emotional responses or not. Some participants believed that dementia posed a threat to their independence, which they highly valued and which had already been threatened to some extent by their stroke. For these participants, the idea of providing information on post-stroke dementia was less acceptable. However, other participants commented that dementia is “so common now” (SS7) and more challenging for family members than for the person with dementia themselves. These participants thought that information about post-stroke dementia would not necessarily be anxiety-provoking for the stroke survivor, but more so for their family members.

SS21: Because I live on my own, I think if I ended up with dementia, I'd probably have to go into a care home.

SS10: To be quite honest, if you develop dementia and you completely lose your memory, in a way, you're in a fortunate position in that you don't know that you're ill.

Nevertheless, some participants acknowledged that it could be useful for family members to receive information about post-stroke cognitive decline and dementia, as this information – although potentially anxiety-provoking and demoralising – could help them monitor cognitive symptoms. One family member (FM11) recognized she now had substantial caring responsibilities for her husband since his stroke, which affected his memory and attention. She readily acknowledged her duty to monitor his cognitive symptoms and felt that receiving information about post-stroke cognitive decline and dementia would have helped her better fulfil this role, despite its potentially anxiety-provoking effect of her.

FM11: They need to relay the information to the next of kin, you know. It needs ... lots of things need to be made, you know, sort of for the person to be made aware of. Because as his carer now, I need to know what kind of signs to look out for and things.

Furthermore, whereas some participants believed information about post-stroke cognitive decline and dementia would be anxiety-provoking for family members, others believed this information would in fact reduce their anxiety about potential outcomes. One family member – who described herself as “that sort of person who deals better with known facts” (FM1) – believed that information on the likelihood of cognitive decline versus cognitive recovery would have reduced her anxiety in the early stages after stroke, as it would have allowed her to work with facts rather than fears and fantasies. However, she acknowledged this information may not be beneficial in the early stages after stroke for family members who deal less well with objective data or for stroke survivors themselves.

FM1: I think [P5] at this stage can hear that sort of statistical information. I don't think it would have been useful for him to have heard that say a couple of months ago, three, four months ago, but I think it would have been useful for me to hear it. [...] I certainly would have benefitted from it. I can tell you right now, that's what I was looking for.

Nevertheless, one participant (FM8) who acknowledged the potential anxiety-provoking impact of information about post-stroke cognitive decline and dementia, but simultaneously recognized the potential benefits of providing this information to family members, referred to the ethical dilemma of providing information to a family member but not to the stroke survivor themselves.

FM8: You can sort of imagine having that conversation with the family but is it fair to not involve the patient, saying “Well, realistically, things are going to decline.” Well, they are, aren't they, for everyone a little bit, but how soon and how fast is impossible [to know]. But it's not motivating and not something to strive for the next level of betterness, if you know what I mean.

Whilst there was substantial individual variability in terms of whether information about cognitive decline and dementia was perceived as potentially anxiety-provoking or depressing, participants were generally more positive about providing this information in the later stages after stroke, rather than the very early stages after stroke. One participant (FM7) described how providing information about post-stroke cognitive stability, decline, or dementia in the later stages after stroke could help stroke survivors and their family members come to terms with and accept that their cognitive skills might not fully recover.

FM7: I would certainly, at the beginning, would rather not know if the outlook is poor because I think that would be a demotivator. I think maybe after a year, it could be helpful because if you're going on and on trying and it doesn't seem to be getting much better, there could be something to be said for saying “Well, I think maybe you've got to settle for this.” It doesn't mean you can't stop trying but you wouldn't perhaps be so frustrated if you felt all your efforts weren't bearing fruit.

Discussion

The present study explored perceived advantages and disadvantages of discussing potential post-stroke cognitive trajectories – encompassing cognitive recovery, stability, decline, and dementia – with stroke survivors and their family members. Results revealed the complexity of this topic, highlighting the need for healthcare professionals to handle clinical discussions about post-stroke cognitive trajectories with the utmost sensitivity. Although participants recognized similar potential advantages (developing realistic expectations and motivating recovery) and disadvantages (increased anxiety and low mood) of providing cognitive trajectory information to stroke survivors and family members in clinical practice, individual participants weighed these factors differently depending on their unique perspectives and the timing of information provision, ultimately reaching different conclusions about whether and to what extent this information should be shared with stroke survivors and their family members. These results support a person-centred approach to delivering information about post-stroke cognitive trajectories in clinical practice.

Our observation that participants reached different conclusions about whether, when, and how information about cognitive trajectories should be provided in clinical practice broadly aligns with Burton et al.'s (2021) conclusion that patients want the “right information at the right time” (p. 9), but that this looks very different from case to case. For example, Burton et al. reported that people with stroke were generally receptive to prognostic information, but this was less often the case for people with brain tumours. Still, whereas Burton et al. (2021) reported that stroke survivors were generally receptive to prognostic information, our results highlight substantial variation in views about discussing cognitive trajectories specifically. Participants in the present study were able to recognize similar advantages and disadvantages of receiving information about cognitive trajectories, but they weighed them very differently, often reaching strong but heterogeneous views about what constituted the “right” information and time for it to be provided. Whereas 77% of healthcare professionals in a recent survey believed that post-stroke dementia risk should be discussed one-six months after stroke (Ball et al., 2022), some participants in the present study believed this information should never be discussed, given its anxiety-provoking nature, whereas others thought any information about cognitive trajectories would be useful for developing realistic expectations. Broadly, these advantages and disadvantages of discussing post-stroke dementia align with those reported by Tang et al. (2019) after a series of semi-structured interviews with stroke survivors, carers, and healthcare professionals: the information was perceived as potentially helpful for preparing for the future, ensuring a timely diagnosis, and for reassurance, but it also had the potential to provoke anxiety. Furthermore, and in line with findings from Burton et al. (2021), our

results highlight the importance of balancing optimism with a realistic picture of the future in prognostic discussions, but there was substantial variability in the *ideal* balance across participants. Our results thus support a person-centred approach to providing information about post-stroke cognitive trajectories in clinical practice.

Lessons on providing information about post-stroke cognitive trajectories, encompassing potential cognitive decline and dementia, may be learned from research on breaking “bad news” in palliative care for other health conditions, such as cancer and multiple sclerosis. Delivering such information can result in emotional distress for both clinicians and patients (Bousquet et al., 2015), so it is critical to establish a person-centred delivery method that minimizes potential negative emotional sequelae on both ends (Dean & Willis, 2016). Various strategies have been established to support best practice in this respect, including the SPIKES protocol (Baile et al., 2000) and Kaye’s 10 step approach (Kaye, 1997), with Royal College of Nursing guidance recognizing that most strategies have a similar overarching structure, involving preparation, communication, planning and follow-up (Royal College of Nursing, 2013). It may be beneficial for healthcare professionals working with stroke survivors to adopt a similar approach when broaching the complex and sensitive topic of potential post-stroke cognitive trajectories (e.g., assess the person’s perception of the topic, obtain their invitation to discuss it, share knowledge and information, address emotions with empathy, and revisit the conversation at a later point if and when appropriate).

The present study has several limitations. Firstly, as discussions about post-stroke cognition may not always be thoroughly integrated into clinical care for stroke (Ball et al., 2022; Hobden et al., 2023), we asked participants to consider how these discussions would have affected them. The hypothetical nature of this line of questioning is a limitation, as stroke survivors and their family members may have responded differently to information about cognitive trajectories in reality. Secondly, although we defined the meaning of post-stroke cognitive trajectories during interviews, participants may not have understood the concept fully, nor recognized the incredible complexity and heterogeneity of post-stroke cognitive trajectories (Demeyere et al., 2019; Milosevich et al., 2023). Nevertheless, our interviews provided rich and meaningful insight into this topic, suggesting that participants sufficiently understood the concept for the purposes of this study. Additionally, only one member of the research team coded and analyzed the interview data, potentially impacting the reliability of the results. However, we note that reliability was not the primary concern of our *reflexive* thematic analysis, as researchers have argued it is more important for this type of analysis to be situated, interpretive, and reflexive (Braun et al., 2019; Braun & Clarke, 2019a).

Overall, the present study supports a person-centred approach to providing information about potential post-stroke cognitive trajectories in clinical

practice. Although participants recognized similar potential advantages and disadvantages of discussing post-stroke cognitive trajectories, they weighed these advantages and disadvantages differently, reaching varying conclusions about whether, how, and to what extent information about cognitive trajectories should be shared with stroke survivors and their family members in clinical practice. Ultimately, information provision and discussions should be tailored to individual needs and preferences, with information related to post-stroke cognitive decline and dementia in particular shared with the utmost selectivity and sensitivity. Healthcare professionals should receive appropriate training to navigate these highly complex and sensitive issues.

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ORCID

Georgina Hobden  <http://orcid.org/0000-0002-4443-296X>

Nele Demeyere  <http://orcid.org/0000-0003-0416-5147>

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