

The Acceptability of post-stroke cognitive testing through the lens of the theory of acceptability, a qualitative study

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ABSTRACT

Background: Cognitive impairment is common after stroke and screening is recommended. However, there is a lack of evidence on the best way to assess cognition after stroke and a tendency to focus on the clinician rather than stroke survivor. The Theoretical Framework of Acceptability (TFA) was developed to better understand the factors that contribute to the acceptability of healthcare interventions from the patient perspective. We aimed to explore the acceptability of post-stroke cognitive assessment from the stroke survivor perspective, using the TFA as a lens.

Methods: We analysed interviews conducted with people admitted to hospital after stroke. Inclusion criteria: ≥ 18 years, able to provide informed consent. Semi-structured interviews were conducted 1–3 weeks after discharge from hospital in the participant's home to explore the experience of cognitive assessment in hospital. Interviews were audio recorded and transcribed verbatim. Data were analysed using framework analysis, with a framework underpinned by the TFA.

Results: Of the 13 participants interviewed, 8 were male, 6 lived in the most deprived SIMD quintile. Ages were 62–84 years. Five themes were identified that describe the factors that influence acceptability of cognitive screening from the patient perspective: (1) participation motives; (2) trust in health professionals; (3) perceived risks of harm; (4) information provision; (5) burden of testing.

Conclusion: Clinical teams should be confident that stroke survivors expect cognitive testing and understand its rational. However, the provision of information and results of cognitive testing should be person-centred.

1. Introduction

Cognitive impairments are reported to affect anything from 30 % to 60 % of people in the first year after stroke depending on the assessment approach [1]. The underlying mechanisms are not completely understood but are thought to include biological, behavioural, and social factors [2]. Clinical practice guidelines recommend screening for cognitive deficits following a stroke [2–4]. This is due to the high prevalence of cognitive deficits in stroke survivors and the potential impact on rehabilitation, hospital stay, quality of life and mortality [5]. Despite the morbidity and impact of cognitive issues, the optimal way of assessing and managing these conditions remains unclear [6]. When considering any intervention, acceptability is an important construct. There have been few theories developed to consider and examine the acceptability of healthcare interventions such as cognitive assessment,

with a few notable exceptions such as the Theoretical Framework of Acceptability (TFA) [7,8].

Memory and cognitive deficits in other domains (e.g. language, executive function) are recognized as being extremely important from the stroke survivor perspective [9–11] and priority setting exercises have indicated that improving the assessment and management of cognitive impairments is important to both stroke survivors and their caregivers [12,13]. Despite this, there is a lack of evidence on the best way to test for cognitive deficits after stroke [14] and a tendency to focus on the clinician rather than the stroke survivor perspective when considering the optimal approach to testing [15].

The acceptability of cognitive assessments to stroke survivors themselves remains an under researched area [16]. Consideration of the patient experience and using this to inform practice is now considered important [17], and is aligned with the shift in healthcare towards

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person-centred care [18–20]. Person-centred care is personalised, coordinated, and enabling [21]. It has been shown in many settings and contexts to enhance adherence to treatment plans [22,23], improve health outcomes and increase participant satisfaction with healthcare services [24,25]. Consideration of person-centred care is now a priority for professional societies and policy makers in many countries including the UK and elsewhere in Europe [26–28]. A fundamental part of person-centred care is ensuring acceptability of healthcare interventions [8,7].

Acceptability is a complex subjective experience likely influenced by many factors [29]. Whilst there is a growing interest around the acceptability of screening tools in healthcare settings, there is a lack of robust and generalizable research on the topic across many clinical fields, including stroke [7,8]. The inherent complexity of the concept of acceptability is reflected in Sekhon et al's Theoretical Framework of Acceptability (TFA), which was designed to address a lack of theoretical foundation to the concept of acceptability in the healthcare setting [7]. An initial framework (version 1) was made, consisting of: burden, affective attitude, ethical consequences, opportunity costs, experience, intention, personal control and treatment control [7]. This was revised iteratively to reduce overlap between themes. The final theoretical framework (version 2) consists of seven constructs that influence the acceptability of interventions: (1) Affective attitude, defined as how an individual feels about taking part in an intervention; (2) Burden, the perceived amount of effort that is required to participate in the intervention with a focus on any associated 'work' (e.g. time, expense, or cognitive effort); (3) Perceived effectiveness of the intervention, defined as the extent to which the intervention is perceived as likely to achieve its purpose; (4) Ethicality, the extent to which the intervention has good fit with an individual's value system; (5) Intervention coherence, the extent to which the participant understands the intervention and how it works; (6) Opportunity costs, the extent to which benefits, profits, or values must be given up to engage in an intervention; (7) Self-efficacy, the participant's confidence that they can perform the behaviour(s) required to participate in the intervention.

Previous studies have used the TFA to understand patients' perspectives around the acceptability of interventions, for example comparing anticipated and experienced acceptability in a population receiving a text message-based intervention to encourage adherence with medications for diabetes [30]; or interviewing people who have inflammatory rheumatological conditions [31] to explore the acceptability of nurse-delivered reviews. The aim of our study was to explore the acceptability of post-stroke cognitive assessment from the stroke survivor perspective, using the TFA as a lens.

2. Material and methods

Ethical approvals were obtained from the Proportionate Review Subcommittee of the Northeast - York Research Ethics Committee (REC number 16/NE/0178) V1.0 10/05/16.

Adult stroke patients admitted to one hospital in Greater Glasgow and Clyde were considered for participation if they were over 18 years and able to provide informed consent. Those with severe aphasia, unable to speak English, or too unwell to participate were excluded. Only those under investigation for the clinical suspicion of stroke were included. The patient's case record was used to describe age, sex, length of stay and stroke type.

Approaches to consent were in waves based on availability of the researcher to conduct interviews. Semi-structured interviews were conducted 1–3 weeks after discharge from hospital in the participant's home to explore the experience of cognitive assessment in hospital. Each participant was interviewed once, and some had family members in attendance during the interviews. Interviews used a mix of open and closed question, as this is preferred by participants and the inclusion of simpler closed questions can reduce cognitive burden. The experienced interviewer was able to explore responses to closed questions to ensure

depth of responses to all the intended interview areas.

There is no consensus on the optimal number of interviews for this form of research. We defined a point of data saturation, not as a static timepoint that could constrain data collection, but based on discussions within the team and an appreciation that new interviews were only confirming previous findings and no new ideas were emerging.

Interviews were audio recorded and transcribed verbatim by a third-party company 'Small Biz Transcripts'. This was checked by two typists, and further sense checked by a researcher against audio recordings to ensure the final transcript drafts were accurate.

Analysis of data was conducted using a framework underpinned by the TFA to understand the experience of in-hospital cognitive assessments from the perspective of stroke patients [24]. The five stages of framework analysis described by Ritchie and Lewis were followed: familiarization, identifying a thematic framework, indexing, charting, and mapping and interpretation [32]. A mixture of both inductive and deductive methods were used. A preconceived framework was utilised underpinned by the TFA, but this was amended and refined during analysis. Care was taken to ensure that findings arose from the data, with careful attention paid to any relevant data that fell outside the framework, or any aspect of the TFA that was not relevant to the data [33,34]. Given the paucity of studies in the field we determined that utilising the TFA as an existing theory in the literature would help contextualise results, but not restrict or obscure what stroke survivors themselves said [35]. One researcher coded all interviews using NVivo 12 (2018, QSR International) with a subset of five transcripts double coded by a second researcher. As a quality assurance step, codes were shared with the researcher who had conducted the interviews for review and comment before the final themes were created. As a final step in analysis, themes were mapped back onto the TFA framework. This was achieved by considering which TFA constructs had the best fit to the themes that had arisen.

Considering positionality, the interviews were conducted by an academic in clinical health psychology. There was no prior relationship between the interviewer and the participants, but she did have knowledge of cognitive screening processes post-stroke. Her area of work is around disability and on the development and evaluation of interventions for people with physical illnesses. She was not involved in clinical care of the participants, or any of the subsequent transcript reading, coding, or theme generation. Data analysis was performed by two general practitioners (GPs) one being an academic GP with a special interest in the workload of self-management for people with stroke. The other GP was undertaking this work as part of his MD program and has an interest in health inequalities. Both had experience of managing the health of stroke survivors in primary care, with limited experience of cognitive screening post stroke. As is often the case with qualitative research, it is possible that previous clinical experiences and research interests could have influenced data analysis. This was mitigated by the double coding of a subset of interviews, the efforts made to allow themes to arise from the data, and discussion amongst the team about coding and themes arising.

Infographics were employed to create a visual map of the major themes and subthemes that emerged from the data and the relationships between them. An infographic was also created to demonstrate how themes mapped to the TFA, and illustrate overlap between themes.

3. Results

Thirteen participants were interviewed with interviews lasting between 16 and 57 min, median 23 min. Demographic characteristics of participants are reported in Table 1. The five themes identified that describe factors that influence acceptability of cognitive screening from the patient perspective are shown were: 1) participation motives; 2) trust in health professionals; 3) perceived risks of harm; 4) information provision; 5) burden of testing (Fig. 1)

Table 1
Demographic data table of Participants & stroke characteristics SIMD (Scottish Index of Multiple Deprivation) [36] 1=most deprived, SIMD 10=least deprived.

Participant	Sex	Age at event	Decile (SIMD)	Stroke syndrome at time of recruitment
1	M	79	9	Left occipital lobe infarct
2	M	84	10	Left lacunar infarct
3	M	81	1	Left hemisphere infarct
4	F	73	2	Multi-focal posterior circulation infarct
5	M	81	2	Right lacunar infarct
6	F	75	6	Right hemisphere infarct
7	M	78	1	Frontal lobe infarct
8	M	62	9	Left hemisphere infarct
9	F	79	2	TIA
10	M	75	7	Right hemisphere infarct
11	F	63	10	Left lacunar infarct
12	M	63	7	Left hemisphere infarct
13	F	76	1	**

* Clinical suspicion of stroke but after full investigation diagnosis was 'probable seizure'.

3.1. Theme: participation motives

Participants expressed a range of motives which contributed to their perception of the acceptability of cognitive assessment. Some participants described concerns about their own cognitive deficits and were motivated by the belief that help could be provided for them if they participated in testing and deficits were identified.

"I feel as though my memory's no' (not) as sharp now. I... you know, I... that. So I want... I want all the help that you can give me" Participant 2

Most participants displayed an understanding that the purpose of the cognitive screening was to identify issues, and they also had an understanding that this testing would be beneficial in terms of grading the severity of any stroke-related deficits. Participants thought this assessment would assist in planning how stroke treatments would proceed for them in a tailored way.

The concept of cognitive assessment as a test which looks at the brain and how it works, and how the stroke might have affected these workings, was almost universal in participant responses. Thus, cognitive

testing was rationalised as part of the battery of assessments that should be expected for all stroke patients in hospital.

"I thought it was part of their job, and they are trying to find out what was wrong with me...to see how far on I was, because...there's different degrees" Participant 3

Comparisons were made to other routine parts of stroke care, such as blood pressure monitoring.

"But I thought, 'well, it's just one of the things they do,' like coming every couple of hours to take your blood pressure..." Participant 9

Some individuals likened participating in testing to a game or puzzle. Their prior experiences of participating in such puzzles was cited as a reason to engage or not engage with the testing, with familiarity and liking puzzles a motivating factor to participate. For these people it was a source of entertainment in hospital at a time when other activities could be limited.

"I was quite enjoying it. Pass the time" Participant 4

Some people directly cited cognitive testing as a personal challenge in which to test themselves. It was something they could engage with, and taking part in the process brought satisfaction, allowing them to draw on their prior skills and experiences to meet the challenge.

"And I told them... if you go tae (to) an exam, read the paper, turn it over, and she says, "How do you know that?" I says, "I got taught that many years ago." Participant 5

3.2. Theme: trust in health professionals

Relationships and trust were a major theme that many participants relayed as influencing their participation in testing. All those asked believed that the cognitive testing had been performed by the correct and appropriately trained individuals. There was an implicit trust that this assessment was for their own benefit. There were no concerns about using the assessments for harmful purposes or that the staff had anything other than the patients' best interests at heart.

"I knew they were doing it for my own good, so I just answered them" Participant 4

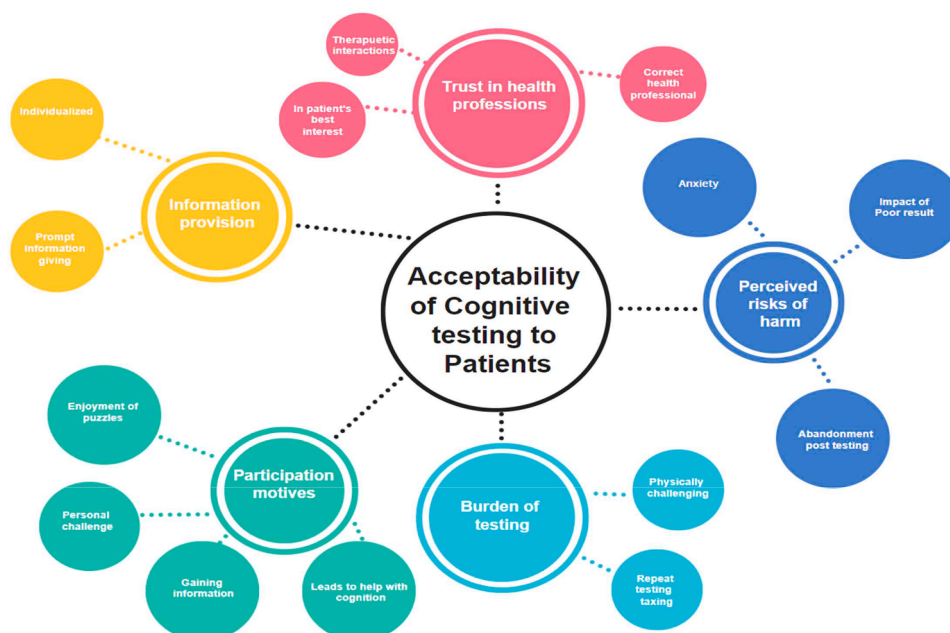


Fig. 1. Conceptual model of acceptability of cognitive testing after stroke.

Participants displayed an awareness that the occupational therapist played a central role in performing cognitive assessment, rather than it being a medical or nursing task, although many noted the benefit of nursing encouragement during assessments. This in turn inspired confidence and trust in the occupational therapist. In one participant this seemed to come at the expense of trust in the medical staff, who were felt not to not be interested in cognition. This comment contrasted with all other participants however who did not comment negatively about other disciplines and interest in cognition.

“...Medical people didn't seem to ask any questions in [cognition]” Participant 1

“I felt as though it was helping me... and then the nurses were encouraging me. Well, it was the physios .and I felt as though they were encouraging me, you know “ Participant 5

Participants displayed mixed views about who could interpret the test results, and who could explain the results comprehensively. One felt that the stroke consultant was best qualified to discuss issues around diagnosis and prognosis.

“Different folk were telling us different things... ..that wasn't right. But I, if you speak to the consultant, you expect the whole picture” Participant 8

Many reported a preference for receiving the results of any memory test performed and the implications of this from the person who tested them.

Many people described a therapeutic benefit from their interactions with clinical staff. The sense they were being listened to and monitored gave reassurance. This appeared to be beyond the utility of the assessments themselves, suggesting that the interactions provided a beneficial effect, underlying the complexity of healthcare interventions of this nature.

“It makes me feel better tae (to) if they're asking me questions. And you feel more, 'Well, they're interested in how you're feeling.” Participant 12

3.3. Theme: perceived risks of harm

One participant spoke of their sense of abandonment post testing, particularly upon discharge from hospital. They had believed that once a problem was identified by the testing process, this would subsequently be acted upon. They expressed frustration around a lack of community support and reported having to be pro-active themselves in approaching organizations and allied health professionals for more information and support. There was also a perception of limited communication from stroke services to community services. For those who recall an identified cognitive deficit being explained to them, there was a sense that once discharged as medically (physically) fit, little thought was given to cognitive aspects.

“The ..test about memory flagged up..my memory's not very good. So they haven't said.. you should do regular memory check-ups. So I'm kind of left on my own to deal with..” Participant 1

Participants reported that repeat testing could induce acute anxiety and made them feel worried, and that the number of times they were asked the same questions provoked fear that their answers were incorrect. A key concern was the potential impact that a diagnosis of poor memory could have upon the participant and the subsequent detrimental effects on mood and rehabilitation engagement.

“I'd be kinda worried if they say there's a problem wi' (with) my memory 'cause I've got a, I would start thinking that I'm in the first stage o' (of) dementia. That would worry me a lot” Participant 4

“The more they kinda asked it, you know, the mair (more) concerned I was getting...What was wrong wi' (with) me...” Participant 12

3.4. Theme: information provision

One participant reported a paucity of information from health professionals around the cognitive assessment they underwent yet subsequently demonstrated a good understanding of the purpose of testing.

Most participants felt that face-to-face discussion of test results would be the best forum, particularly if a poor result was obtained. Most wanted results of all tests and their implications explained to them clearly and in a timely fashion. One participant thought that their family should be alongside them as they received the results. Individualised information provision tailored to personal preferences was important.

“I would obviously prefer my wife to be there...I think when someone is being told something they should have a relative with them.” Participant 11

3.5. Theme: burden of testing

While most participants were content to participate in the process of testing and reported its benefits, some did identify burden of testing as an obstacle to their participation. One participant described initially enjoying testing, but that it had become taxing and burdensome with repeated testing during their inpatient stay, and this had impacted upon their engagement with the process. This served to illustrate the risks of test fatigue, if too much is undertaken too quickly or without time for the participant to have adequate rest between assessments. This concept of burden was distinct from the perceived harms of testing where participants might experience worry or anxiety and reflects instead the cognitive load burden placed upon participants to engage with the process.

“So, the first paper I got was... circles and ovals and . But the second one I got.. didn't bother looking at it, I just... I just started circling them, you know?... I didn't bother concentrating on..” Participant 5

Another participant spoke about their physical difficulty when it came to completing some of the tasks that required hand co-ordination and dexterity and cited this as a significant issue in terms of their engagement. Being unable to write presented a physical burden for this participant in contrast to the mental burden the other patient highlighted.

Oh yes, you can't write. I mean I'm bad enough just now with my hands, because my arm's actually hopeless, you know, to use. My hand's okay, I can use that, but I can't write, I can't, you know” Participant 1

3.6. Mapping of themes to the TFA

Fig. 2 shows how the five themes correspond to the TFA constructs and includes quotes from participants. Overlap between themes is also demonstrated. Some themes mapped to more than one TFA construct, for example, the theme 'participation motives' fits into both TFA constructs 'affective attitude' and 'ethicality'. The theme 'information provision' mapped to both TFA constructs 'intervention coherence' and 'perceived effectiveness'. The theme 'burden of testing' aligned to the TFA constructs 'burden' and 'self-efficacy'. Other themes mapped to just one construct, for example the theme 'trust in health professionals' mapped to the 'affective attitude' construct of the TFA and the 'perceived risks of harm' theme mapped to the 'opportunity costs' construct. No data or themes fell outside of the TFA framework.

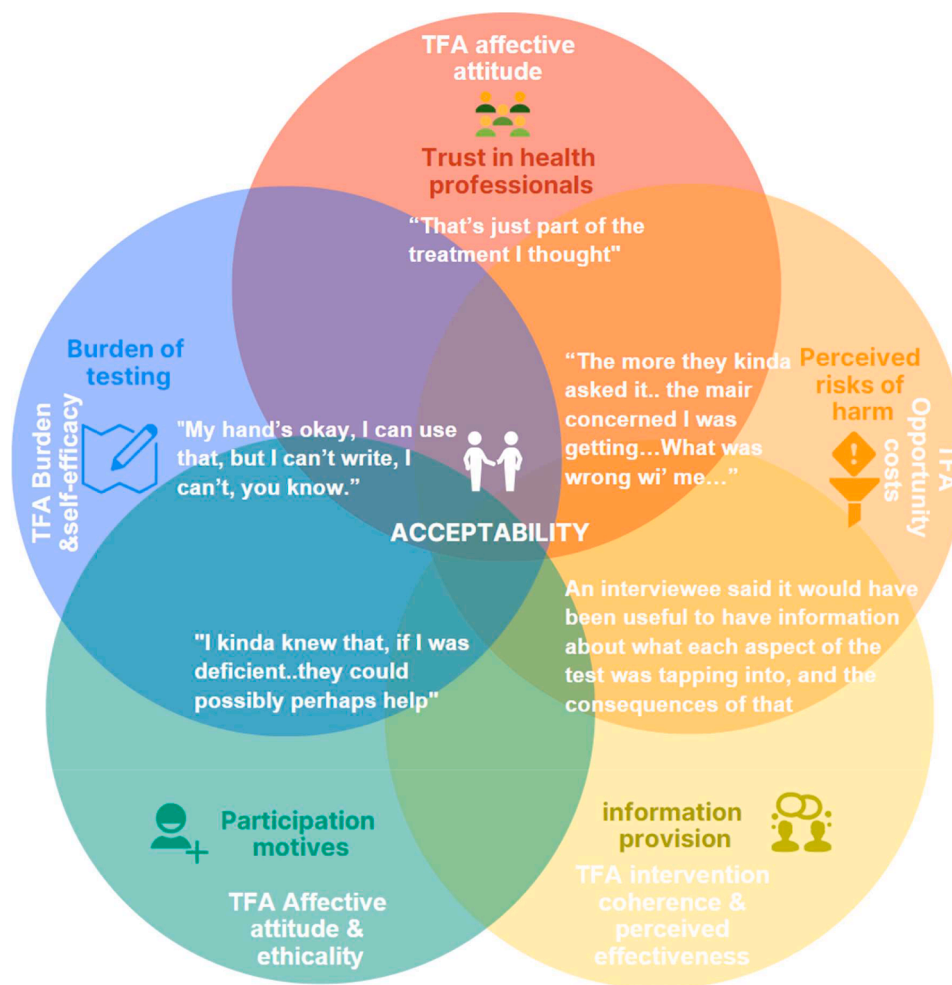


Fig. 2. Emergent themes mapped onto the constructs of the TFA, with selected quotes. Overlap between themes is demonstrated by circles overlapping.

4. Discussion

This study adds to the limited literature exploring cognitive assessment in stroke survivors admitted to hospital. We decided to seek only the patient perspective as this has often been overlooked, in preference to the clinician's viewpoint. Our approach adds novelty as we employed the TFA to evaluate the acceptability of cognitive assessments. We found five major themes that influenced acceptability: participation motives, trust in health professionals, perceived risk of harm, information provision, and burden of testing. Taken together these five themes contain the essential components required to ensure acceptability i.e., a trustworthy professional taking account of their individuality to deliver an assessment and explain the results, in a manner suited to them, which aids in their diagnosis, and minimises potential burden and harms.

4.1. Results in context of previous literature

Most participants expected and engaged with cognitive assessment. Some were keen to reach a better understanding of their diagnosis, or cognitive issues, a sentiment echoed in a U.S study examining acceptability of dementia screening in primary care settings [37]. Here acceptability and participation were positively correlated with subjective memory complaints. A comparable study of cognitive assessment acceptability in a multiple sclerosis population noted one participant remarking "If such tests are just standard, people wouldn't be scared off...it is incredibly relevant, just as relevant as a blood sample..." [38] a belief that our cohort concurred with. A pilot study examining

acceptability of cognitive tests in an Australian Aboriginal population, also found that testing was welcomed and for some participants likened to 'playing a game' and 'a good challenge' [39].

However, patients wished to have information provision regarding their tests and results in a form they choose, and this should be understood and respected by clinical staff. A key consideration was the impact that a diagnosis of poor memory can have upon stroke survivors and how this could have a detrimental impact on mood and rehabilitation engagement. This finding is mirrored in a study of those undergoing post stroke dementia screening [40]. Likewise, in a Swedish population participant concern about abandonment post testing with an 'abnormal' test result emerged [41].

Frequent testing was associated with perceived burden and could provoke anxiety. The need to have a benchmark of cognitive status may have to be weighed against need and frequency of testing. Guidelines tend to focus on the benefits of cognitive testing and little attention or content is devoted to the potential for harm from these assessments. This should be a consideration for clinicians going forward to facilitate building and maintaining therapeutic relationships.

Most prior research on the acceptability of cognitive testing has primarily been in non-stroke populations [42,43], involving quantitative surveys. In Canadian patients with brain metastases, 92 % of those undergoing treatment reported that cognitive screening was 'only mildly or not at all inconvenient' [43]. Furthermore, in a German study exploring patient-reported acceptability of cognitive screening pre- and postoperatively in those with a brain tumour, the team concluded that testing was 'well accepted by the participants' [42]. As these studies

sought to quantify acceptability using questionnaire metrics, rather than explore the experience qualitatively, the findings cannot be directly compared with these results. However, their message that patients are accepting of cognitive testing is congruent with our results.

To date only one other paper has specifically examined the experiences of stroke survivors who underwent cognitive assessment during an acute stroke care admission [44], although not examining the acceptability of cognitive assessment. They employed a reflexive thematic qualitative analysis of 26 participants and presented themes within '3 key phases of [the] assessment': (1) Before assessment, encompassing a lack of explanation and consideration of the assessment as useless; (2) During assessment, which included varied emotional responses, perception of purpose of the assessment, perception of cognitive deficits, confidence in cognitive function, and assessment administration style; (3) After assessment, in which they found that feedback can impact self-confidence and efficacy, and that non-tailored feedback and clinical jargon were viewed as unhelpful. This study has many parallels with our findings. The concerns over a lack of explanation about the purpose of the assessment provides corroboration of our finding that tailored information giving is crucial. One difference between the studies is that most of our participants seemed to understand the purpose of the assessments, perhaps due to better explanation by healthcare staff, or perhaps this was influenced by the short time between assessment and interview. Anxiety over testing emerged in both studies. Interactions with the health professionals administering the assessment was also mentioned as important, with positive relationships framed as coming from 'patient and gentle' clinicians. On the other hand, vague feedback and jargon were unfavourably viewed, with a clear preference for person centred and individually tailored information giving.

Thus, across a heterogeneity of study populations, screening tools and methods of data analysis, there are findings that generally align with the findings from this study. Cognitive testing is seen as a routine part of healthcare, which is especially valued by those with concerns over cognitive symptoms. However, there is some potential for burden and harm if testing and disclosure of results is not handled well.

4.2. Strengths and limitations

One strength was the limited exclusion criteria employed, allowing those with any level of physical disability and those with a degree of reduced cognition to take part. However, it is likely that the more physically disabled, and those with more severe cognitive problems were still underrepresented. By the very nature of the consent process, selection bias is likely to be present, despite our inclusive approach. Thus, the participants in this study may have a more favourable attitude to cognitive testing than those stroke survivors who declined to participate. Inclusion of people from a variety of socioeconomic backgrounds can be considered a strength, as can the mix of male and female participants. Although we did not aim for a generalisable sample due to the exploratory nature of the research, inclusion of people with a variety of demographic characteristics allowed us to explore a range of opinions from those with different backgrounds and circumstances.

The short time from discharge to interview of participants (3 weeks or less) is likely to have aided participant recollection of events. Furthermore, as interviews are conducted within the participants own environment, rather than a healthcare setting, and not with a member of the clinical team, courtesy bias is less likely to be a factor. The multi-disciplinary nature of the research team including a psychologist, two GPs and a stroke consultant should be viewed as a strength, as all assessed the themes for face validity. The mix of inductive and deductive methods allowed examination of data through the lens of the TFA while ensuring that findings arose truly from the data. Subsequent mapping of each emergent theme back onto the TFA constructs offered further validation of the data.

The study also had a number of limitations. It could be considered a weakness that the interviewer was not the person undertaking the

coding, despite the primary coder becoming immersed within the data to become familiar with it. Another potential limitation of this study was that only basic demographic and clinical data were collected. Other relevant characteristics such as ethnicity, occupation, educational status, and information on premorbid cognition were not available. We also did not know which cognitive assessments had been undertaken in each participant, and their scores.

4.3. Future research and clinical recommendations

Further studies of stroke survivors could examine the acceptability of different assessment tools, and how to communicate those tools and results. The timing of assessments and how they may influence participation is also a key area where further work could broaden our understanding. The generalizability of the TFA for understanding the acceptability of other post stroke interventions such as speech and language therapy post stroke would also be beneficial.

In practice, clinicians should consider acceptability when deciding on the need and frequency of cognitive testing, as well as the type of test employed. As with the use of any test designed to answer a clinical question, the potential harms of cognitive testing need to be carefully considered. Both physical and mental burdens should be taken into account when considering timing, duration and repetition of testing. A tailored approach to sharing results should be taken, taking into consideration factors such as the patient's desire to have other family members present and how detailed the results should be. There was an almost universal view that results should be explained, and their implications made clear to participants. Assessments must be patient centred, and acceptable, for the reasons that the participants themselves outlined, but also because of the previous discourse around the benefits of patient-centred approaches for both patients and clinicians [21,22,24].

5. Conclusion

We explored acceptability through the lens of the TFA which we found to be a useful framework. Patients admitted with stroke expect cognitive testing, but the approach to testing and sharing of results could be improved. These findings can aid clinicians and policy makers in implementing acceptable cognitive assessment procedures in acute stroke care.

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CRedit authorship contribution statement

David McMahon: Writing – original draft, Writing – review & editing. **Diane Dixon:** Investigation. **Terry Quinn:** Conceptualization, Funding acquisition, Writing – review & editing. **Katie I Gallacher:** Data curation, Formal analysis, Methodology, Writing – original draft, Writing – review & editing.

Declaration of Competing Interest

We can attest & declare that we have no statements of interest.

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