

The experiential impacts of cognitive function tests upon men with dementia and their carers

Edward Tolhurst

School of Social Work, Allied and Public Health, Faculty of Health Sciences, Staffordshire University

Abstract

Critical evaluation is undertaken of the impacts of cognitive function tests upon the experience of men with dementia and their carers. There has been a strong biomedical focus on the efficacy of cognitive function tests, with little attention granted to their broader experiential effects. Primary data from a qualitative study are utilised to demonstrate these impacts. These are presented under four key themes: concerns with regard to the validity of tests; impacts upon self-esteem; shaping carers' perceptions of the condition; and tests being viewed as a resource that is offered in the absence of more person-centred support. Further research, which specifically focuses on the experiential impacts of cognitive function assessments, is therefore required as a matter of urgency.

Keywords

Biomedical model; cognitive function tests; dementia; masculinity; person-centred care; personhood

Introduction

Dementia is a neurodegenerative condition that is associated with disturbance of multiple functions including language, comprehension, thinking and memory (Hughes, 2011). In the United Kingdom (UK) it is estimated that about 850,000 people have dementia (Alzheimer's Society, 2014). A contributory resource available to the clinician when diagnosing and monitoring dementia is the cognitive function test¹, using an instrument such as Mini-Mental State Examination (MMSE), Addenbrooke's Cognitive Examination (ACE III), Montreal Cognitive Assessment (MOCA), or the Clock Drawing Test. This enables examination of factors such as short-term and long-term memory, concentration, language and executive function (NICE-SCIE, 2007, p.160). It should be noted that mental health professionals use a range of other assessment tools alongside cognitive function tests. For example, within the diagnostic process a resource such as MMSE is principally a screening tool that highlights whether further assessments are necessary.

Cognitive function tests have received considerable (international) research scrutiny from a biomedical/psychiatric perspective. This is predominantly focused on an evaluation of the validity and reliability of testing procedures; for example, the value of tests to the clinician as a component of diagnostic and monitoring processes. Additionally, the aim is to seek a link between cognitive function and other behavioural symptoms or dispositional attributes. A selection of recent articles reinforces this point: Lerner (2012) evaluates the utility of the

¹ To avoid excessive repetition, the terms 'cognitive function test' and 'cognitive function assessment' are employed interchangeably in this article.

Montreal Cognitive Assessment as a screening instrument, alone and in combination with the MMSE; Milian et al, (2012) compare the effectiveness of the Mini-Cog, MMSE and the Clock Drawing Test within a memory clinic; Hausdorff & Buchman (2013) consider the links between gait speed and dementia with reference to measures of motor and cognitive function; Pavlik et al (2013) evaluate the link between insulin levels and cognitive function in people with Alzheimer's disease; and Valyudhan et al (2014) review the validity of a number of tests in different clinical settings.

This biomedical focus on the efficacy and empirical utility of tests has been inadequately supplemented by research that considers the wider impacts of these assessments on their recipients' well-being. The actual impact of tests upon people with dementia, and also their family members, has received very little academic consideration. This article sets out to address this shortcoming: evaluation of the experiential impacts of cognitive function tests is undertaken with reference to qualitative research that sought the views of men with dementia and their spousal carers.

Literature context

Experiential dimensions of cognitive function tests in biomedical literature

As highlighted above, cognitive function tests receive intense scrutiny from a biomedical perspective, with the focus on the efficacy of instruments abstracted from their broader effects upon experience and relationships. However, clinically-oriented authors have acknowledged the experiential impacts of assessment practices:

"Cognitive testing can be very upsetting for the person concerned. It reveals the person's problems in a stark way. It needs to be undertaken with care and under the right circumstances. It is important that the things the person can still do should also be emphasized" (Hughes, 2011, p.88).

In addition, it has been acknowledged that assessment scales should be of an acceptable format so that they do not "upset, exhaust or embarrass the patient or assessor" (Sheehan, 2012, p.350). Nevertheless, such perspectives provide a very limited counterbalance to the one-sided focus on the scientific efficacy of assessment tools. It is notable that even a key introductory text for clinicians on cognitive assessments (Hodges, 2007) makes no reference to their potential experiential outcomes.

This point is underscored with reference to a quantitative psychiatric study that did focus on the potential negative emotional impacts of testing processes. This study found that, following cognitive testing, some form of distress was present in 70% of a sample of 154 patients with Alzheimer's disease (Lai et al, 2008). The conclusion of this article however focuses on the prognostic significance of distress in determining appropriate interventions rather than seeking solutions with regard to how distress caused by testing processes could be mitigated. The orientation, even for a medically-oriented study on subjective distress, remains the enhancement of assessment efficacy rather than seeking to reduce their negative emotional impacts.

Cognitive function tests in social scientific literature

While the biomedical model has predominated, the experiential impacts of cognitive function assessments have received limited scrutiny within broader academic literature. Drawing upon data from qualitative interviews Keady & Gilliard (1999) highlight that assessment schedules are constructed on the basis of cognitive loss and assigning scores to the

measurement of incapacity, with the person with dementia situated as a passive recipient within this professional process: the focus of such tests is therefore intrinsically focused on impairment and deficit. In a later text the authors discuss how test participants were presented with insufficient information on the purpose and outcomes of the tasks that they were undertaking (Keady & Gilliard, 2002).

Sabat (2001) argues that methods of assessment could be based more on the flow of natural social interaction so that remaining abilities are recognized, supported and even enhanced. This point is underscored in a later text which reports on a case study of a woman with Alzheimer's disease: there could also be "dissociation between cognitive function as measured by standardised assessments and cognitive function as revealed in social situations" (Sabat & Gladstone, 2010, p.61).

Endorsement of the potentially negative impact of testing upon self-worth is provided by Beard (2005) who undertook a qualitative study of the assessment process. Respondents depicted negative responses such as shame, disgust and disbelief during both the testing process and upon receiving the results.

It is also important to recognise that current public policy in many countries is aimed at increasing the rates of diagnosis of dementia (Couteur et al, 2013). For example, in England 'Living Well with Dementia: a National Dementia Strategy' aims to ensure that significant improvements are made to dementia services across key areas which include earlier diagnosis and intervention (Department of Health, 2009). Further to the perspective of Lai et al (2008) discussed under the previous heading, a recent study that evaluated the complete diagnostic process highlighted that: "Many experienced tests and assessments as distressing, sometimes in settings that were perceived as alarming or potentially stigmatising by association" (Manthorpe et al, 2013, e69). The policy endeavour to increase diagnosis rates, allied to the potential for cognitive testing processes to cause distress, emphasizes that the experiential impacts of assessment processes upon recipients must now begin to receive an appropriate degree of social scientific scrutiny.

This article builds upon the perspectives of this literature but offers particular insights into how the experiential impacts of cognitive function tests extend beyond the actual site of assessment, shaping ongoing experience and relationship dynamics.

Method

Findings are utilised from a qualitative study that explores the experience of dementia for men with the condition, and their carers. Fourteen dyads were involved in the study² (13 of the dyads were married mixed-sex couples, while one was same-sex and not married.) These couples took part in semi-structured joint interviews, with the person with dementia and carer interviewed together in the family home. Each set of respondents was interviewed on two occasions, with a six-month interval between interviews. This approach was employed to ensure greater depth of experiential insights.

Only men with dementia were interviewed in the study (and all but one carer was female) which limits the gender-based transferability of the findings. Nevertheless, this design feature enables clear insights into how cognitive function tests impact upon men with dementia and their carers, and it also enables scrutiny of how cultural constructions of masculinity might shape the experience of cognitive function tests.

Respondents were recruited via National Health Service (NHS) Trusts in England, and dementia support groups. The mean duration of the interviews was 70 minutes. There were no exclusion criteria with regard to the type of dementia: one participant had vascular dementia, and another had dementia with Lewy bodies. The other 12 men had Alzheimer's.

² Two carers were also interviewed on a one-to-one basis as the person with dementia did not have capacity to take part. Cognitive function tests were not discussed by either of these carers.

The age range of the men with dementia was 58 to 89; the age-range of the carers was 52 to 84. One man with dementia was Afro-Caribbean, the rest of the sample was White-British. Analysis of interview transcripts was undertaken with reference to narrative thematic analysis (Riessman, 2008). The principal researcher undertook close reading of the text and manual noting, which led to the identification of narrative themes.

This research adopted a broad orientation, seeking respondent perspectives on relationship dynamics within the spousal dyad and other family members. Views were also sought on professional support that had been accessed, as well as plans to access support in the future. While the interviews covered the diagnostic process in general terms, there was no explicit intention to seek perspectives on cognitive function tests; that is, no question relating to these interventions was presented directly by the interviewer. Matters relating to these tests were therefore introduced independently by respondents in this study³. Experiential impacts of cognitive function tests were identified as a key theme in interviews with 10 of the 14 dyads. As this matter arose unprompted within a significant proportion of the sample, this presents an initial indication of the experiential resonance generated by this professional intervention.

Table 1 summarises the characteristics of those dyads in the sample (10 out of 14) where experiential dimensions of cognitive function tests were identified to present particular significance. There were no clear patterns differentiating those who directly raised such matters and those that did not i.e. with reference to participants' ages or the time that has elapsed since diagnosis.

Table 1: Dyad characteristics (at date of first interview)

Man	Age	Carer	Age	Time since diagnosis	Type of dementia
Oliver	58	Elizabeth	55	Six months	Alzheimer's
David	64	Florence	52	Six months	Alzheimer's
Timothy	64	Martin	56	Six months	Lewy body
Nicholas	66	Caroline	67	One year	Alzheimer's
James	67	Irene	66	Two years	Alzheimer's
Simon	75	Sally	64	One year	Alzheimer's
Robert	76	Rachel	73	One month	Alzheimer's
John	82	Anne	74	Three years	Vascular
Sam	83	Eleanor	77	Three years	Alzheimer's
Marcus	89	Michelle	84	Five years	Alzheimer's

³ Respondents did not state the particular mode of test that was undertaken, but it is clear from the presented data that they are referring to some form of cognitive function assessment: if tests are not mentioned directly then participants refer to the types of question asked, or scores/points associated with the intervention.

Findings and discussion: experiential impacts of cognitive function tests⁴

Questioning the validity of tests

A feature of cognitive function tests that raised queries from respondents related to validity; that is, how accurately tests represented functioning and abilities. This was highlighted by Florence: she felt that her partner was practically orientated and that, even prior to the onset of dementia, he would not have been dispositionally suited to the abstract nature of cognitive assessments:

"I think there are certain people who will never have been able to do those tests terribly well. And I found it quite fascinating really because I don't think David even at the top of his mental ability, they were things that he could have done, he just didn't have that processing sort of capability [...] That's what slightly worries me about the diagnostic side of things, that you think, 'is it that he never had the skill?'"

(Florence – carer)

This also suggests that there is a possibility that people with dementia could find the process of testing frustrating if they do not have the disposition or aptitude for such tests. The cognitive function test highlights specific limitations, even though the person with dementia might have a range of other skills and abilities.

Another carer Irene stated that particular test conditions hinder her partner from responding in a way that captures his knowledge level. Irene suggested that her partner was uneasy with the process: the following quote commences with her stating the type of question that causes him to worry:

"Who's the Queen?' you know. And he looks to me to see who the Queen is. But he does know who the Queen is, but they worry him asking him. If you asked him, cos he knows you, or I did 'What's the Queen's name?' – 'Elizabeth of course', thinking 'What did you ask me that for, is she doing a crossword?' You know, 'Why's she asking me? I know very well who the Queen is'. But when this lovely lady asked him, he hadn't got a clue"

(Irene – carer)

Alternatively, it is perceived by Caroline that her partner's disposition to undertake cognitive tests to a high standard (as a consequence of his previous employment as a teacher) might have contributed to delays in diagnosis:

"You had 99 out of a hundred, so that was good. And I said to them you can give him these questions all you like, he's used to it; that was his job"

(Caroline – carer)

Guidance for health and social care professionals in the UK underscores that multiple factors will shape the outcome of tests, including the person with dementia's educational level, language and prior level of attainment (NICE-SCIE, 2007), and such limitations with regard to MMSE have been recognised for some time (e.g. Anthony et al, 1982). The

⁴ Names of respondents and professionals have been changed. An ellipsis inside square brackets shows that some text has been removed from a quote. This is to assist with the presentation of data, it does not alter the meaning of responses. The 'cleaning' of text is consistent with narrative approaches (Riessman, 2008).

findings of this study raise a query as to whether professional knowledge on the nature of assessments (for example, that assessments offer circumscribed insights into cognitive functioning, which are mediated by multiple factors) is cascaded to the point of the clinical intervention. The interview excerpts above show carers concerned that extraneous factors will shape assessment outcomes, rendering the results questionable. This perhaps shows that these concerns could have been more effectively assuaged by professionals managing the diagnostic or monitoring process. Further to the findings of Keady & Gilliard (2002), it appears that people with dementia and their carers still remain insufficiently well informed with regard to the nature and purpose of tests.

Impacting on self-worth

Perspectives expressed within this study demonstrated that cognitive function tests have the capacity to pose a challenge to the self-worth of the person with dementia. Oliver's statement below offers a clear demonstration of the potential impact of tests upon the participant's self-concept:

"When the nurse came out and she tested me that's when I realised how bad I was. It shocked me a bit"

(Oliver – person with dementia)

It has been highlighted that people might not attribute their situation to the neurological manifestations of dementia, but that the process of diagnosis can lead to them being socialised into perceiving forgetfulness, or other personal changes, as symbolic of disease (Beard & Fox, 2008). The aforementioned quote perhaps indicates the initial stages of this process of socialisation for Oliver.

David also expressed disquiet about his initial test performances, before proceeding to assert how he has improved:

"They gave me tests and for the first couple of, the first two or three tests I really struggled [...] I suppose once they actually, definitely diagnosed that I'd got early stages of Alzheimer's, at that point they began to input with drugs. Things like that which gave me a lot of security and made me feel a lot happier and I felt that I wasn't as dim as I thought I was [laughs]. Because I really had a bad time before this happened. I was really struggling and felt embarrassed about struggling. But the girls that have come out to me [...] they've put me on different tests and as I work through the tests I've got better and better at working out the tests. In fact the last test I had I think I got 34 out of 35"

(David – person with dementia)

Tests appear to have informed the diagnostic process. David is therefore now taking medication and this, allied to a sense of clarity on his condition, seems to have made a positive impact. However, this process also appears to have contributed to a sense that David considered himself to be defective to some extent, and (further to Beard, 2005) such imposed definitions could lead to a subjective feeling of shame. As tests can elicit intensely negative emotional reactions, this powerfully emphasizes that consideration of the experiential dimensions of cognitive function tests must be embedded within diagnostic and monitoring processes.

It is notable that, while cognitive function tests received significant scrutiny from respondents, assessments such as brain scans tended to be discussed briefly and in neutral, descriptive terms. For example, David referred to how the scan was used to confirm that he

had dementia, but this particular intervention did not appear to present the same threat to his sense of self-worth. In a similar fashion to cognitive function tests, the findings from a brain scan could demonstrate the impact of dementia in stark terms. However, as concerns with scans were not expressed by participants in this research this suggests that difficulties with assessment processes do not simply relate to indications of decline. A brain scan is focused on a biological level of existence that resides to some extent beneath the expression of interactionally expressed abilities, while cognitive function assessments measure facets of being that relate directly to socially-articulated personal identity. That is, they are conducted within the social domain of human relationships where personhood can be undermined (personhood is discussed under the next heading).

In the excerpt above, David also discussed how his test scores have improved and appears to draw confidence from this situation. The fact that he specifically refers to his improvement in these tests indicates how the assessment process had impacted negatively upon his self-esteem. Renewed confidence related to this improvement potentially presents further problems as he is using an increased test score to bolster his sense of competence and self-worth. However, this generates a situation whereby the negative emotional impacts of a reduced score in the future might be felt acutely. When self-worth becomes coupled with the outcome of a quantitative test, this presents an ongoing challenge and accordingly a threat to the person with dementia's emotional well-being. Assessment predicated on a deficit model therefore presents issues whether scores decrease *or* increase.

Sam also discussed his capacity to complete tests with a high score. This again presents a situation whereby a reduced score in future tests could erode feelings of personal worth, particularly as the assessment involves a seemingly cherished skill:

"The nurse would give you 100 questions you know, and I could almost get them all right. I could get 90 odd, 99 a couple of times. Asking where you are and all this, then they get you doing mental arithmetic. But I was always pretty good at maths and I could get 90 odd every time"

(Sam – person with dementia).

The quote below shows another response to a cognitive function test that might relate to the defence of self-worth:

Anne: "He gave him a test of write down all the words beginning with 'p'. Well he expected him to put 'pot', 'pan', 'pie'. No, he put 'physiotherapist', 'physician' and Kevin [health professional] was just absolutely gob-smacked [...] So he said to him, 'Can't you think of a simple word beginning with 'p'?' and John just went, 'Yeah well, okay, "piddle"' [laughs]."

John: "What else?"

Anne highlights how John was able to perform at a level that exceeded the expectations of the clinician. John does not elaborate on his reaction to the testing process. Nevertheless, his approach to the test could be a means by which he sought to retain control over the process: being asked a relatively simple question could potentially have challenged his sense of self-worth, so his proposal of complex words beginning with 'p' demonstrates the extent of his enduring capabilities.

Such reactions also prompt the requirement to recognise how cognitive function assessments relate to broader experiential factors. One such overlapping theme identified in this study was 'skills and competence'. Men offered examples of how skills had been retained, or by presented accounts of former activities which demonstrated their abilities (often related to employment). It is also crucial to note how gender might intersect with the

experience of cognitive function tests. Labels associated with illness related to passivity, dependence and a subordinated status (Charmaz, 1994) clash with societal notions of masculinity, which are predicated on autonomy and competence. While generalisations should be avoided (and factors relating to skills and competence will be important to women as well) men might feel particular pressures as a consequence of cultural expectations associated with masculinity: *being good at what you do* is a strong masculine-gendered trait (Coston & Kimmel, 2013, p.197). A positive self-concept associated with productive labour could be of particular salience to men: aspects of identity related to personal competence might therefore be significantly challenged by the process of cognitive function assessments.

Shaping perceptions of carers

Perceptions of the person with dementia's functioning and abilities are also shaped by cognitive function tests. For example, carers might be heartened by a score in a cognitive test, particularly if it is an improvement on a previous test. This situation is reminiscent of David's improved scores discussed under the previous heading. Sally highlighted how happy she was with her partner's score in a recent test:

"About every six months he goes back [to the hospital]. And they do the memory test. Because the last time we were quite thrilled weren't we, because he got 26 out of 30. So he's better. But he's still on his medication"
(Sally – carer)

While a good test score can have positive emotional effects, this raises implications for the impact of future tests: increased scores offer a fragile reassurance that is at risk of being punctured. An improved score could place the person with dementia and their carer in a precarious emotional position underpinned by a hope, with regard to the anticipated trajectory of the illness, which is unlikely to be reinforced by further cognitive assessments. It has been argued that an important part of the assessment process should be instilling hope in the lives of people with dementia and their carers (Keady & Gilliard, 2002). However, the nature of hope in relation to cognitive function tests requires more extensive consideration. The findings from this study indicate that cognitive function tests can actually generate a form of hope that lacks sufficiently credible foundations: ongoing testing as part of monitoring processes tethers hope precariously to the score of a narrow, quantified deficit-model of assessment.

The score from a cognitive function test also offers a resource by which the condition can be understood and defined by the carer. In the quote below a carer highlights that scores in monitoring tests have diminished and then juxtaposes this with the increase of personal support that is now required. While this might be a reasonable inference to make in this instance, it does show how cognitive function scores are used to make sense of the carer's situation and to some extent label the person with dementia's behaviour:

"He had dropped by about three points on that which was okay, Fiona [health professional] said understandable. But he's just had the other one last week, the next six-month one and he dropped another three points, so we are down into the teens now with it and of course things change [...] He's needing more help with, well, a lot of things, a lot of prompting with the clothes going on back-to-front and all those things you expect with dementia"
(Martin – carer)

A further example is presented by Rachel who draws upon the score of a test to confirm her prior assumptions of her partner's decline. This also demonstrates how the results of a

test can be interpreted with reference to the frame of deficit and decline. This might orient carers towards how the test outcome reflects declining function, rather than how remaining faculties and abilities can be encouraged and sustained. The following quote also demonstrates a direct comparison with another individual's score. Such comparisons are problematic, as extraneous factors (such as educational background) will shape test outcomes:

"Robert has been to the memory clinic and had a memory test. I know that our friend was 19 out of 30 and I'd always said that Robert would be worse and he was. He was 16 out of 30 which is very bad"

(Rachel – carer)

A cognitive function test therefore ascribes a quantitative marker to the person with dementia's situation. A test showing reduced scores might therefore prompt queries over capacity and abilities to a greater degree than the influence of the dementia requires. Carers might also act in a manner shaped by the score of a cognitive function test, underplaying (or overstating) their partner's abilities.

The focus on cognitive function scores is compatible with the understanding of dementia as a biomedical phenomenon; that is, as a terminal condition defined by neurodegenerative changes. However, the person with dementia's experiential domain is not only determined by neurological factors: people with dementia retain an intrinsic personhood that should be respected, and that experience can be enhanced by adjusting interactions and the environment so that this personhood can be more effectively articulated. Personhood is thus shaped by the context of personal relationships and is even conceived as a *status bestowed* upon the individual by others (Kitwood, 1997). Therefore, the responses of carers and other family members to a perceived label conferred by a cognitive function test could have significant implications for the person with dementia.

Such a perceived label might have particular resonance when intersecting with the experience of those negotiating the biographical disruption (Bury, 1982) prompted by the onset of dementia. It is important to note that cognitive function tests are likely to have taken place within a more extensive and discursive clinical interaction. Nevertheless, despite this broader context, the process of testing still has particular experiential salience for carers. When faced with a disruptive and disorientating situation, a test which applies a discrete quantitative score to the condition offers certain clarity and this accordingly elevates perceptions of the test score's significance. A clear numerical indicator places a neat and tangible definition upon complex and demanding personal circumstances, as well as presenting a tangible point of comparison across the monitoring process.

Under certain circumstances, however, changes to a person with dementia's behaviour might relate to factors that have no correlation (or a mediated correlation) with a cognitive function test score. This score could therefore have a direct impact upon the person with dementia, by focusing on their personal limitations. In addition, relational and contextual factors could be influenced by the results of an assessment, as a result of the carer and family members also responding to the test outcome. The assessment process could actively contribute to negative social conditions that compound the challenges encountered by people with dementia. This relates to the concept 'malignant positioning' (Sabat, 2001): by employing a deficit model, cognitive function tests have the scope to contribute to malignant positioning, by focusing attention on the deleterious impacts of the condition. Presenting an indication of cognitive decline in such a stark manner could obscure recognition of other elements of the person's identity, and the breadth of social personae that underpin their personhood.

Indicating a lack of person-centred support

Perspectives presented in this research also suggest that a lack of socially-oriented support could lead to the narrow and functional process of cognitive assessment being viewed as the central component of professional input. This relates to the principle of person-centred care. Professional support needs to recognise that dementia cannot be understood solely with reference to its biological basis. The personhood of the person with dementia needs to be supported and it is therefore crucial to account for the psychological and sociological dimensions of the condition (Brooker, 2007).

While presenting a stoical view that not much additional assistance could be offered, Michelle highlights the limited and repetitive nature of professional interventions that she encounters with her partner:

"We did get an appointment at the centre where he goes three times a week; we went there to see a person. But it was the usual thing; they draw a clock and put the numbers on. Exactly the same things you do every time. Suppose there's nothing else you can do really"

(Michelle – carer)

A similar perspective is demonstrated by Irene below. She discusses how their new healthcare arrangements do not compare favourably with previous support. Whereas support formerly had a social basis, now all that appears to be offered is an assessment that is perceived to offer little utility. The fact that Irene refers to the previous health professional by name on three occasions in this excerpt indicates that an interpersonal affinity was forged with this professional. This contrasts with the more impersonal and test-based input that is now offered:

"They don't do anything. We just go once a year and they ask you to spell 'world' backwards or something trivial like that. But when the girls used to come out to him, Melanie [health professional] used to come, oh he loved Melanie. She used to come and have a cup of tea with him and it was lovely and he related to Melanie"

(Irene – carer)

This shows an association of cognitive tests with a lack of broader support that could address more personal and experiential requirements. Tests appear to be regarded as a task undertaken by the professional in the absence of more socially-oriented input. As a consequence the compatibility of cognitive function tests with principles of personhood and person-centred care can be queried: an excessive focus on measures of cognitive processing could marginalise recognition of the significance of social and relational dimensions of the person with dementia's support requirements. This view is in accordance with Manthorpe et al (2013) who also found that those undergoing assessments did not experience them as patient-centred.

Conclusion

Evaluation of the experiential impacts of cognitive function tests demonstrates that these assessments present manifold implications for people with dementia and their carers. Cognitive function tests can: prompt concerns with regard to their validity; generate embarrassment and worry; inflate a sense of hope that is unlikely to be sustained by further testing; present a quantitative marker that might excessively shape perceptions of the condition; and be viewed as a resource that is offered in the absence of more socially-

oriented support. These findings highlight that the role of assessments should be aligned with greater professional awareness of experiential impacts of these tests. Hopes, self-esteem, concerns and worries can become anchored to these discrete totals, and fluctuations in performance are presented in stark terms.

Cognitive function tests should not therefore be viewed as discrete assessment tools: attention needs to be directed to understanding their broader impacts upon the well-being of people with dementia. The multiple and varied experiential impacts of cognitive function tests highlighted in this research demonstrate that it is inappropriate for these tests to reside almost exclusively within one particular mode of professional discourse i.e. the biomedical model.

Under the current clinical approach to cognitive function testing, there is a clear requirement for the nature and implications of tests to be communicated effectively to people with dementia and their carers. This includes conveying the circumscribed role that testing plays within diagnostic and monitoring processes. Appropriate communication could thus help to ameliorate the experiential effects of cognitive function tests. As noted above, tests are only a contributory resource within broader interventions. Cascading this actuality more clearly can help people with dementia and their carers to recognise that testing does not comprise the central component of professional input.

In addition, the intensive experiential impacts highlighted in this article indicate that the present approach to cognitive function testing warrants scrutiny in itself. Following Sabat (2001), tests which are more socially and practically oriented could offer the scope to evaluate the impacts of dementia without placing such direct scrutiny on narrow cognitive performance. Even if performance and capabilities decline, the focus would remain on what the person is able to do, rather than on the numerical outcome of a test.

Although this research did not set out to evaluate cognitive function tests directly, the experiential impacts of these assessments were vividly conveyed. It is therefore insufficient that cognitive function tests should be scrutinised solely with reference to their measurement validity and reliability; the way that these tests make people feel should also be closely scrutinised. Accordingly, cognitive function tests require broader scrutiny beyond a focus on their scientific efficacy. This research has shown that the process of cognitive function testing can potentially exacerbate the challenges of living with dementia. Research that adopts a direct focus on the experiential impacts of cognitive function tests upon people with dementia and their family members is therefore required as a matter of urgency.

Ethics

Ethical approval for this research was obtained from the Staffordshire University Faculty of Health Sciences Research Ethics Committee and the NHS Research Ethics Committee.

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