International Journal of Therapy and Rehabilitation

Enabling people with communication and cognitive impairments to provide feedback on service satisfaction – development and reliability testing of an adapted pictorial questionnaire

--Manuscript Draft--

Manuscript Number:	ijtr.2019.0061R1
Article Type:	Original research
Keywords:	Test-retest reliability; Agreement, Patient Satisfaction; Brain injury; Aphasia; Cognitive Communication Disorder.
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Enabling people with communication and cognitive impairments to provide feedback on service satisfaction – development and reliability testing of an adapted pictorial questionnaire

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KEY WORDS (x6): Test-retest reliability; Agreement, Patient Satisfaction; Brain injury; Aphasia; Cognitive Communication Disorder.

KEY POINTS:

This study provides evidence for the reliability and validity of an adapted, pictorial, patient satisfaction questionnaire based on the principles of Talking Mats, (a dynamic communication framework).

The results demonstrate that the APQ is a reliable tool, with test-retest reliability at over 90% for people with aphasia.

The APQ has a role to play in supporting people with communication impairments in providing user feedback within rehabilitation as well as other hospital settings.

Wider use of this approach may enhance the quality and reliability of patient feedback that is increasingly mandatory in health services around the world, as well as improve the health care experiences among persons with communication impairments by more actively engaging them in the provision of service feedback.

Background:

Current UK policy requires clinical services to obtain feedback on patient satisfaction using validated tools (Department of Health, 2010, NHS Improvement, 2018). All adult patients are now expected to give feedback including those with communication impairments. There is considerable pressure on planners, commissioners and providers of health and social care services to involve users at all levels of care whether individual, service or strategic (Clare and Cox, 2003).

Despite this, there remains a lack of research in relation to seeking personal views from people with acquired communication impairments (Dalemans, van den Heuvel and de Witte, 2009; Carlsson, Patterson, Scott-Findlay, Ehnfors and Ehrenberg, 2007; Luck and Rose, 2007; Kagan and Kimelman, 1995). It is often assumed this population provide interview responses that are unreliable, misleading, difficult to interpret, or requiring specialist expertise by virtue of the presence of brain damage. (Connect, 2007; Clare and Cox, 2003). They are therefore excluded.

A number of common communication impairments can arise from an acquired brain injury such as a stroke or trauma. Aphasia is an acquired language disorder affecting an individual’s understanding of the spoken word, speaking, reading and writing (Murray and Chapey, 2001). Cognitive Communication Disorder (CCD) is difficulties in communicative competence arising from underlying cognitive impairments (attention, memory, organization, information processing, problem solving and executive functions) and in the context of intact basic language functions such as syntax and semantics (Togher, 2014). Variability may be more expected in this population given the nature of attentional/information processing deficits. Motor speech disorders affect the planning, programming, control or execution of movements required for speech (Duffy, 2013). Cognitive communication disorders are the most common communication impairment following brain injury, occurring in up to 70% of cases. Aphasia and dysarthria are both present in up to 30% of cases (Togher 2014).

Successful attempts have been made to develop specific measures validated to support the participation of persons with communication impairments in relation to mood and the impact of aphasia on the life of an individual (Visual Analogue Self Esteem Scale (VASES), Brumfitt and Sheeran, 1999; The Communication Disability Profile, Swinburn and Byng, 2006). Despite these measures, there appears to be a lack of literature successfully demonstrating tools which evaluate service satisfaction in a communication impaired population .

Talking Mats™ is an evidence-based framework which facilitates feedback from individuals with a variety of communication impairments (Murphy, 1998; Murphy, 1999; Boa and MacFadyen, 2003; Murphy, Tester, Hubbard, Downs and MacDonald, 2005; Bornman and Murphy, 2006; Gray, Murphy and Cox, 2007; Murphy, Gray, van Achterberg, Wyke and Cox, 2010). The framework is based on sets of picture symbols presented to the person with the communication difficulty. The individual's view is represented by placement of each picture under certain headings or visual analogue scales. Further details can be found in the methodology section. Talking Mats™ is not designed to be used as a stand-alone tool, but rather as a resource employed alongside total communication methods such as facial expression, eye contact, pointing, gesture and body language (Murphy et al, 2005).

Brown, Dendy and Murphy (2000) demonstrated that Talking Mats™ could be used to elicit service user feedback on respite care services for those with learning disabilities. Murphy, Tester, Hubbard, Downs and MacDonald (2005) succeeded in establishing service user feedback from the frail elderly in care homes experiencing dementia, aphasia or deafness. To date it has not been tested as a tool for obtaining feedback from brain-injured adults undergoing in-patient rehabilitation.

The Regional Hyperacute Rehabilitation Unit (RHRU) at Northwick Park Hospital is a tertiary regional inpatient neuro-rehabilitation service in North West London. The majority of patients treated have complex neurological disability with severe physical, cognitive and/or communicative deficits. In 2010, the unit's multidisciplinary team noted that a significant proportion of this patient group struggled to complete the hospital's standard patient satisfaction questionnaire, and we explored ways to support them to report their experience of our in-patient rehabilitation programme. We modified the standard written patient feedback questionnaire using Talking Mats™ principles. The self-reported standard written questionnaire (SWQ) comprised 21 questions with Likert scale responses. The adapted pictorial questionnaire (APQ), using Talking Mats™ principles, comprised the same questions and optional responses, but was pictorial, interactive and facilitated by a trained therapist. Whilst gathering the same information as the SWQ, the APQ was designed to facilitate comprehension for those with receptive impairments and to enable those with little or no expressive language to share their thoughts and opinions. However, although it had been informally piloted with a small number of purposively selected patients with language impairment in the course of its development, it had not been formally validated.

Aims

This study examined the test-retest reliability (repeatability) of the adapted pictorial patient satisfaction questionnaire over time. We also examined the level of agreement between responses to the APQ and SWQ.

Methods

Setting, Design and Timescale

This was a prospective, pilot-cohort, reliability study conducted in a single specialist in-patient rehabilitation unit (the RHRU at Northwick Park Hospital) during a three-month period in 2013.

Participants

Patients who met the inclusion criteria were approached by the researcher (Author KC) during the last four weeks of their inpatient rehabilitation programme and invited to participate in the evaluation. All 26 patients approached consented to participate.

The inclusion criteria were as follows:

1. Acquired brain injury of any cause
2. A communication disorder (language, cognitive or motor speech) of any severity as a result of their brain injury
3. Having received a period of in-patient rehabilitation on the RHRU
4. Demonstrating mental capacity to consent to participate in the research.

The principal exclusion criterion was inability to give informed consent, as per the conditions of the National Research Ethics Service (NRES) committee.

Research Ethics permission

The research project received ethical approval by the NRES West Midlands Committee – Coventry and Warwickshire; Research Ethics Committee reference 13/WM/0055.

Questionnaires and administration

Consenting participants completed both the APQ and, if able, the hospital's standard written questionnaire (SWQ) on two occasions (test-retest design), within the same day but a minimum of 2 hours apart. Participants engaged in an active rehabilitation programme between occasions of questionnaire completion, to distract from remembering prior responses. The last twelve recruited participants were also asked by the author which questionnaire they preferred following administration of both formats.

Insert figures 1a and 1b here

a) The standard written questionnaire (SWQ)

The SWQ is shown in Figure 1a. Whilst a staff member was present during completion of the SWQ, no help or facilitation was provided by the staff member to the participant. This was to mimic usual practice for completion of this type of questionnaire in most hospital settings. A staff member was present for both forms of questionnaire completion (SWQ and APQ) which also avoided possible administration bias.

b) The Adapted Pictorial Questionnaire (APQ)

The APQ is shown in Figure 1b. It comprises the same questions as the SWQ but crucially is interactive in keeping with the Talking Mats™ approach (Murphy 1998; Murphy and Cameron, 2008; Brown, Dendy and Murphy, 2000). The participant depicts their response by placing small 5x5cm picture cards on a textured mat below a three or four point visual analogue scale in Likert format (‘yes / no / sometimes’; or ‘very good / good / fair / poor’).

Development: Pictures to represent the concepts were primarily taken from Boardmaker™ software (King Software Development, 2004) as per the creation of Talking Mats™. Where no suitably representative image could be sourced from Boardmaker™, an appropriate image was taken from the internet, chosen by consensus within the unit’s speech and language therapy (SLT) team. The APQ was informally piloted with three purposively selected aphasic service users as part of its development to obtain feedback on whether the picture was representative of the concept it was portraying. None of the three patients reported the need to modify the pictures.

Ensuring consistency of administration: The lead researcher (Author KC) attended Talking Mats™ training and conducted cascade training to other SLT staff in the department to ensure consistent administration of the questionnaires in keeping with Talking Mats™ principles. Participants were asked each question and shown an appropriate picture to match the question. They were then asked to place the picture under one of the symbols in the visual analogue scale. Where necessary (and in keeping with Talking Mats™ principles) facilitation was provided by the administrators in the form of repeating the question, chunking the question into smaller sections, stressing key words, and/or checking the participants' response.

Reducing administration bias: Participants completed one each of the SWQ and APQ on two occasions (Time 1 and Time 2), between two and eight hours apart. On each occasion, administration was conducted by a member of the unit's SLT team (which consisted of four qualified SLTs and two Masters-level students). Counterbalancing of both questionnaire type and administrator was designed to administrator confounds. Participants were randomly allocated to a group A or B (n=13 in each) to determine the order of questionnaire administration. Time 1 and Time 2 questionnaires were administered using a different member of the SLT team. The lead researcher always administered one of the time points, with the second SLT member randomly allocated. Wherever possible, data were collected within one working day (eight hours) to reduce the likelihood of overnight changes in opinion in relation to service satisfaction.

Analysis

Likert responses for both the SWQ and APQ were converted to a numerical score and transferred to the study database. Responses were analysed using Cohen's Kappa coefficient (κ) for questions with three ordinal response options (i.e. yes / no / sometimes), and linear-weighted Kappa (κ_w) for those with four ordinal responses (i.e. very good / good / fair / poor). Kappa values were calculated together with 95% confidence intervals (CI) and probability values, and were interpreted according to Landis and Koch (1977): <0 = 'poor' agreement; 0.01-0.20 = 'light' agreement; 0.21-0.40 = 'fair' agreement; 0.41-0.60 = 'moderate' agreement; 0.61-0.80 = 'substantial' agreement, 0.81-0.99 = ‘almost perfect’ agreement. Questions were considered to be reliable if $\kappa = \geq 0.41$, indicating at least moderate agreement. It is acknowledged this is lower than the usual threshold of substantial agreement ($\kappa = \geq 0.61$) but is still better than chance performance and a more realistic target for those with cognitive and communicative impairments where variability is more expected given the nature of attentional/information processing deficits and impaired basic language functions following brain injury.

Test-retest reliability and agreement between overall scores was tested with Cohen’s Kappa Coefficients (κ). Whole group (n=26) and sub-group analyses (by type of communication impairment: participants with aphasia (n=11) and participants with cognitive communication disorders (CCD, n=11)) were conducted as follows:

1. Test-retest reliability of the APQ – agreement between Time 1 and Time 2
2. Test-retest reliability of the SWQ – agreement between Time 1 and Time 2
3. Agreement between the two versions of the questionnaire (APQ versus SWQ).
    a. Whole group analysis involved pooled samples of all 26 participants. Responses to all 21 questions responses from the APQ from both Time 1 and Time 2 were compared with the same pooled sample for the SWQ.
    b. Subgroup analysis involved pooled samples for the 11 participants in each group (i.e. patients with aphasia and those with CCD). Response to all 21 questions responses from the APQ, at both Time 1 and 2 compared were again with the same pooled sample for the SWQ i.e. 22 questionnaires per group.

We also explored the test-retest reliability and agreement of individual questions separately for patients with aphasia and those with CCD. We hypothesised that neither type of questionnaire would be entirely reliable for patients with CCD due to short term memory and attentional deficits. We deliberately included participants with dysarthria because it was necessary to have at least a proportion of patients able to complete both the APQ and the SWQ in order to make comparison between them. Unfortunately data for participants with dysarthria were too small for meaningful analysis as a distinct subgroup.

Missing data: No missing data were imputed. If patients failed to complete a question, that question was excluded from the analysis of total scores.

Findings

Demographics

Within the sample of 26 participants the mean age was 44 years, (range 17-75), male to female ratio 14:12. Of these, 19 (73%) had a primary medical diagnosis of stroke; six (23%) had traumatic brain injury, and one had a hypoxic brain injury. Primary SLT diagnoses included aphasia (n=11), cognitive communication disorder (n=11) and dysarthria (n=4) as documented following formal SLT assessment. The demographics for each of these groups are shown in Table 1. Nine of the 11 (82%) of participants with aphasia had only mild or moderate auditory comprehension impairments and seven (64%) had only mild or moderate reading impairments.

Insert Table 1 here

Of the 26 participants, three had significant difficulty completing the SWQ. One participant with aphasia was unable to read the SWQ at all, but was able to complete the APQ. Two participants with CCD failed to complete the SWQ fully, but *were* able to report their level of satisfaction fully using the Talking Mats™ approach. Some participants therefore had missing data for some questions on the SWQ, but there was no consistent pattern in the items missing. Items with missing data were excluded from the analysis.

Whole group analysis

a) Test retest reliability between Time 1 and Time 2

To gain an overall impression of reliability, we examined responses across the entire participant group. The results are summarised in Table 2.

Insert Table 2 here

Pooling all questions for all patients, there was 'substantial agreement' between Times 1 and 2 for both the APQ (κ_w =0.72, (95%CI 0.68, 0.76)) and the SWQ (κ_w =0.78 (95%CI 0.74, 0.82). When examined individually, 14/21 (67%) of the questions in the APQ and 17/21 (81%) in the SWQ showed at least 'moderate' test retest reliability (κ >0.41).

b) Agreement between questionnaire types

Agreement between the APQ and SWQ (tested using pooled samples from both time periods) was also in the 'substantial' range (κ_w =0.76 (95%CI 0.73, 0.79), with 17/21 questions (81%) showing at least 'moderate' agreement (κ >0.41).

Sub group analyses:

Test retest reliability and agreement between the questionnaire types was also analysed separately for groups of patients with different communication impairment: those with aphasia and cognitive communication disorder (CCD).

a) Test retest reliability

In their responses to the APQ, patients with aphasia showed better test retest reliability than those with CCD (91% of questions showing at least 'moderate' agreement compared with 62%). A broadly similar pattern was seen for test retest reliability of responses to the SWQ (86% vs 67% showing at least 'moderate' agreement).

Table 3 shows the detailed question-by-question breakdown of kappa values for test retest reliability in the APQ, comparing the two types of communication disorder. Table 4 shows the same for the SWQ.

Insert Tables 3 and 4 here

b) Agreement between questionnaire types

For patients with aphasia, 86% of questions showed at least 'moderate' agreement between the two questionnaire types (APQ and SWQ) compared with only 67% in participants with CCD (see Table 2). Table 5 shows the detailed breakdown of agreement between the two questionnaire types (APQ and SWQ).

Insert Table 5 here

Patient preference

The sample of 12 participants (seven with CCD, four with aphasia and one with dysarthria) were asked at the end of Time 2 which questionnaire format they preferred. Five participants preferred the written questionnaire, and a further five expressed no preference for either format. However, two (one with aphasia and one with CCD) stated they preferred the APQ:

- One said: *"Pictorial. Too much writing, the other one. Any picture is key. I don't like the writing. I don't understand words on the page".*
- Another said*: "I've had a bit of brain damage. Everything is not really clear to me. This [Talking Mats™ questionnaire] is a lot clearer to me than that [written] questionnaire. That questionnaire [written] wouldn't sink in".*

Data was not routinely collected on the reasoning behind why the SWQ was preferred. However two participants reported:

- "*I prefer the written one personally. But for someone not understanding it [the Talking Mats™ one] would be very good*".
- *"For me [pointed to the written questionnaire] but for others [pointed to the Talking Mats™ questionnaire"*

Post hoc analysis

In order to reduce an administrator confound across time, two different members of staff collected the data at Time 1 and Time 2. It was possible, however, that differing therapist styles may have influenced patient responses and altered levels of agreement. A post-hoc analysis was therefore conducted to compare agreement for questionnaires delivered by “Therapist 1” (Author KC, the lead researcher) with those delivered by “Therapist 2” (one of 5 others). Levels of agreement were no better for questionnaires delivered by a constant individual, “Therapist 1”, suggesting that this was not an influential confound in this study. (Data is not shown but available on request from the corresponding author).

Discussion

This study reports the first evaluation of an adapted pictorial questionnaire based on the Talking Mats™ technique as a means to obtain feedback regarding service satisfaction in an in-patient rehabilitation setting from patients with communication difficulties who may have difficulty completing a standard written questionnaire. The overall findings suggest that both forms of the questionnaire were repeatable (κ_w =0.72 - 0.78) and showed ‘substantial’ agreement between each other (κ_w =0.76). The aphasic participants were somewhat more consistent using the APQ (achieving over 90% acceptable test retest reliability), whilst, if anything, patients with CCD were slightly more consistent using the SWQ but still only achieved ‘moderate’ test retest reliability in two-thirds of the questions. Talking Mats (Murphy 1998) includes the use of verbal information within its dynamic framework. Simplifying statements/ questions, chunking information and stressing key words to support participants’ understanding, together with the richness gathered from participants through their additional nonverbal and/or verbal cues adds to effective feedback and may account for improved outcomes for aphasic participants.

The study was originally conceived to address the challenges that aphasic patients may face in providing feedback. Our findings broadly mirror those of other authors. Brennan, Worrall and McKenna (2005) stress that written material is often inaccessible for people with aphasia, and Murray et al (2005) and Brown et al (2000) demonstrated that Talking Mats™ enabled individuals to provide their opinions of services received in care homes and respite units. We had also anticipated that cognitive impairments (particularly those in relation to reduced short term memory, and attention/concentration) would impact on this group’s ability to respond consistently using any form of questionnaire (Brennan, 2005).

For this first evaluation, we deliberately included patients with a wide range of communication and cognitive difficulties, because it was necessary to have at least a proportion of patients able to complete both forms of the questionnaire in order to make comparisons between them. As noted above, for this particular group, the aphasic patients were marginally more consistent with the APQ and those with CCD were more consistent with the SWQ. Importantly though, three patients (one with aphasia and two with CCD) who were unable to complete the standard written questionnaire were enabled to provide feedback using the pictorial version. This emphasises the importance of producing feedback questionnaires in a range of different formats to cater for patients with different types of challenges for communication.

Our findings also raise questions about the validity of patient reported outcome measures as a whole for those with CCD – including, for example the increasingly large number of older patients using NHS services some of whom will have dementia or other forms of cognitive decline. The Department of Health in England (2010) and NHS Improvement (2018) emphasise that seeking feedback from all patients, is not optional but mandatory, regardless of diagnosis. This study selected patients who had the mental capacity to consent to participate in the research, but even this relatively able population had some difficulty with completing both types of questionnaire reliably. This highlights the need, not only to use the best tools available, but for more research to understand which types of tool may be most accessible for which patients and so optimise the chances of receiving meaningful feedback.

In this study, participants were given no assistance to complete the SWQ to mimic usual practice. If the SWQ had also been administered with facilitation (for example in the form of repeating the question, chunking the question into smaller sections, stressing key words, and/or checking the participants' response etc.) it is possible patients with CCD would have had greater success. So, whilst not tested in this particular study, it is possible that a therapist-facilitated SWQ may be beneficial for some patients. Nevertheless, patient preference should be taken into account, and the fact that some patients preferred the APQ argues for the wider application of the Talking Mats™ approach (or equivalent) as an option for seeking feedback on service satisfaction.

Limitations and future directions for research

The authors acknowledge a number of limitations to this study.

- This was a small sample from a single centre. The sample size is below the ideal number for the statistical tests used. A commonly-used power calculation for weighted Kappa statistics is $2K^2$ (where K is the number of response levels within items of an ordinal scale, Cicchetti and Fless, 1977). With up to 4 response levels, this would require a sample size of n=32. Whilst the pooled sample from Times 1 and 2 (n=52) met this requirement, the sample of n=26 for agreement between questionnaires fell short and the sub-analyses for different types of communication disorder further reduced the sample size, thus affecting the statistical power of our results.
- ‘Moderate’ agreement (κ=≥0.41) was taken as the threshold for acceptable reliability instead of the more usual requirement of ‘substantial’ agreement (κ=≥0.61). This may have enhanced the impression of reliability, but was chosen for pragmatic reasons, acknowledging the challenges for this particular group of patients.
- With occasional short gaps of as little as 2 hours, it was possible that some patients could have remembered their responses between Time 1 and Time 2. However, given the large number of questions (n=21), we consider this unlikely.
- Patients with aphasia typically have significant dyslexia (Wilson 2008). In this sample, selected on the basis of being able to give informed consent, 7/11 aphasic patients had only mild–moderate deficits in written comprehension and thus may not have been representative of the aphasic population as a whole.

- Brennan et al (2005) report patients may be limited in their comprehension of aphasia-friendly written information if the pictures chosen do not adequately represent the concept of the text. It is possible that while every effort was made to ensure clarity and relevance of the symbols selected for this study, abstract concepts such as respect and dignity may not be as appropriately represented as others.
- Only 12 out of 26 participants were asked their preference as to which questionnaire they preferred.

Despite these limitations, we believe that this first published application of the Talking Mats™ technique as an aid to reporting patient satisfaction in a rehabilitation setting is a significant advance that is worthy of further exploration. Future directions for research include increasing sample size, diversifying participant characteristics, and extension to a wider range of rehabilitation and other hospital settings, including stroke and care of the elderly wards. Importantly, we need to have a better understanding of which types of tool may be best to capture feedback from which types of patient.

Conclusion:

This study provides evidence for the test retest reliability and validity of an adapted pictorial, questionnaire based on the principles of Talking Mats™ as a tool for capturing patient satisfaction for patients with various types of communication disorder. The results were comparable with those of a standard written questionnaire, but patients with aphasia performed more consistently using the pictorial version and some with cognitive communication disorder also preferred it.

Further exploration is necessary but wider use of this approach could potentially enhance the quality and reliability of patient feedback that is increasingly a mandatory requirement in health services around the world.

References

Alexander, M. Benson, D. and Stuss, D. (1989) Frontal lobes and language. Brain and Language **37**, 656-691

Brennan, A. Worrall, L and McKenna, K. (2005) The relationship between specific features of aphasia-friendly written material and comprehension of written material for people with aphasia: An exploratory study. *Aphasiology,* **19:8**, 693-711

Boa, S. and MacFadyen, L. (2003) Goal setting for people with communication difficulties. *Communication Matters*, **17:3**, 32-34.

Bornman, J. and Murphy, J. (2006) Using the ICF in goal setting: Clinical application using Talking Mats. *Disability and Rehabilitation: Assistive Technology*, **1:3**, 145-154.

Brown, L. Dendy, M. and Murphy, J. (2000) Respite review: Obtaining the views of the users. *Communication Matters*, **14:2**, 26-27.

Carlsson, E. Paterson, B. Scott-Findlay, S. Ehnfors, M and Ehrenberg, A. (2007) Methodological issues in interviews involving people with communication difficulties after acquired brain damage. *Qualitative Health Research*, **17**, 1361-1371.

Ciccheti DY and Fleiss JL. Comparison of the null distribution of weighted kappa and the C ordinal statistic. *Applied Psychological Measurement* 1977, **1,** 195-201

Clare, L. and Cox, S. (2003) Improving service approaches and outcomes for people with complex needs through consultation and involvement. *Disability and Society*, **18:7**, 935-953.

Coehlo, C. DeRuyter, F. and Stein, M. (1996) Treatment efficacy: Cognitive-communicative disorders resulting from traumatic brain injury in adults. *Journal of Speech and Hearing Research*, **39**, S5-S 17.

Connect – the communication disability network (2007) *Including people with communication disability in stroke research and consultation: A guide for researchers and service providers*. Connect, London.

Dalemans, R. van den Heuvel, W. de Witte, L. (2009) Facilitating the participation of people with aphasia in research: A description of strategies. *Clinical Rehabilitation*, **23**, 948-959.

Department of Health (2010) *Equity and Excellence: Liberating the NHS*. The Stationery Office Limited, London.

Duffy, J. R, (2013) *Motor Speech Disorders: Substrates, Differential Diagnosis, and Management.* Elsevier Mosby

Gray, C. Murphy, J. and Cox, S. (2007) *How talking mats can help people with dementia to express themselves*. The Joseph Rowntree Foundation, York.

Intercollegiate stroke working party (2016) *National clinical guidelines for stroke.* 5th edition, Royal College of Physicians, London.

Kagan, A. and Kimelman, M. (1995) Informed consent in aphasia research: Myth or reality? *Clinical Aphasiology*, **23**, 65-75.

Kearney, C. and Trull, T. (2014) *Abnormal Psychology and Life: A Dimensional Approach*. Cengage Learning.

Landis, J. and Koch, G. (1977) The Measurement of Observer Agreement for Categorical Data *Biometrics*, **33:1**, 159-174.

King Software Development (2004) *Boardmaker®* Mayer-Johnson

Luck, A. and Rose, M. (2007) Interviewing people with aphasia: Insights into method adjustments from a pilot study. *Aphasiology*, **21:2**, 208-224.

Murphy, J. (1998) Helping people with severe communication difficulties to express their views: A low tech tool. *Communication Matters*, **12:2**, 10.

Murphy, J. (1999) Enabling people with Motor Neurone Disease to discuss their quality of life. *Communication Matters*, **13:2**, 3-7.

Murphy, J. Tester, S. Hubbard, G. Downs, M. and MacDonald, C. (2005) Enabling frail older people with a communication difficulty to express their views: The use of Talking Mats as an interview tool. *Health and Social Care in the Community*, **13:2**, 95-107.

Murphy, J. and Cameron, L. (2008) The effectiveness of Talking Mats with people with intellectual disability. *British Journal of Learning Disabilities*, **36**, 232-241.

Murray, L. L, and Chapey, R. (2001). Assessment of language disorders in adults. In R. Chapey (Ed.), *Language intervention strategies in aphasia and related neurogenic communication disorders* (pp. 55-126). Philadelphia, PA: Lippincott, Williams & Wilkins.

Murphy, J. Gray, C. van Achterberg, T. Wyke, S. and Cox, S. (2010) The effectiveness of the Talking Mats framework in helping people with dementia to express their views on well-being. *Dementia*, **9:4**, 454-472.

NHS Improvement (2018). Patient experience improvement framework https://improvement.nhs.uk/documents/2885/Patient_experience_improvement_framework_full_publication.pdf.

Rose, T. Worrall, L. Hickson, L. and Hoffman, T. (2011) Aphasia friendly written health information: Content and design characteristics. *International Journal of Speech-Language Pathology*, **13:4**, 335-347.

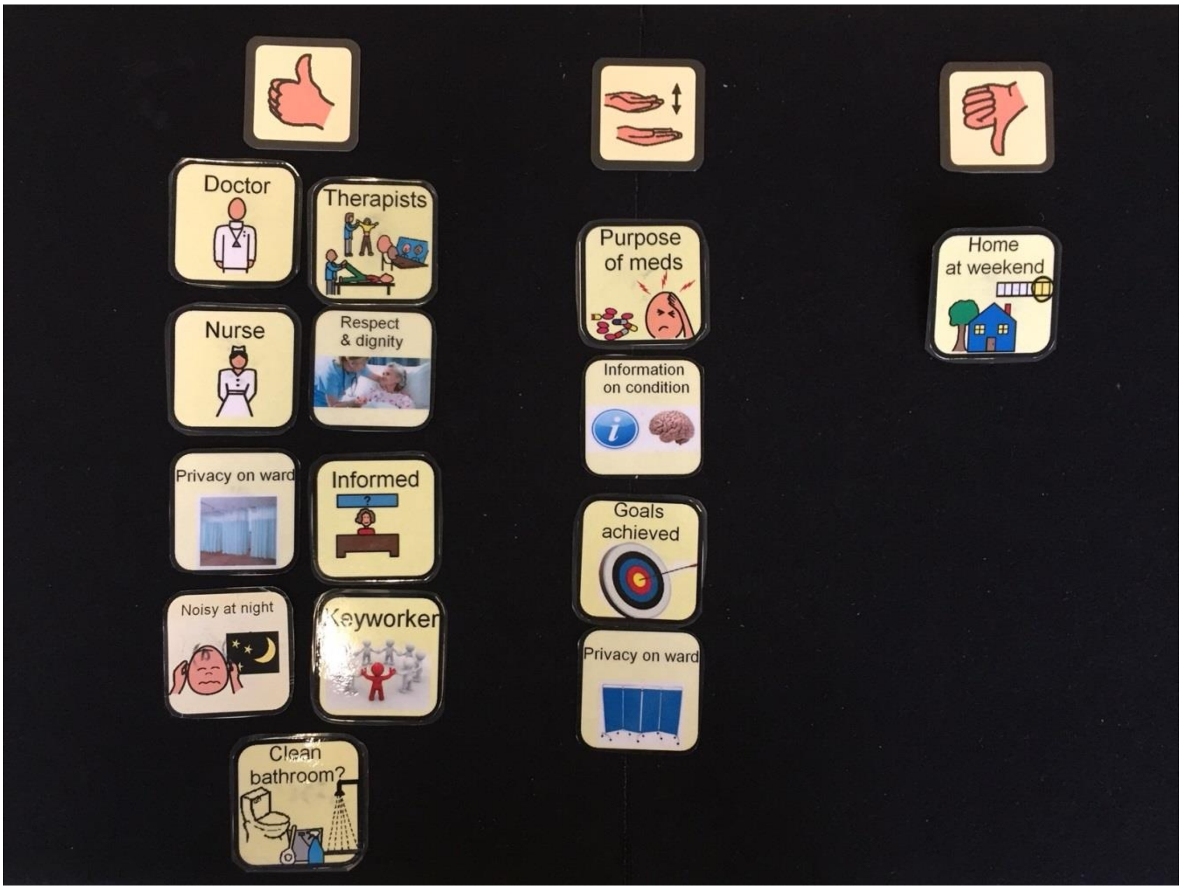
Togher, L (2014) An inquiry into the prevalence of different types of speech, language and communication disorders and speech pathology services in Australia. https://www.aph.gov.au/DocumentStore.ashx?id=27d0bfda-8b17-4f9d-a043-b292da882b92&subId=32884. Accessed 14.08.19.

Wilson, J. (2008) The nature and prevalence of alexia in aphasia. http://etd.fcla.edu/UF/UFE0022185/wilson_j.pdf Accessed 14.08.19.

Figure 1a shows a sample of questions from the standard written questionnaire (SWQ)

The "Standard Written" Questionnaire		Yes Always	Yes Sometimes	No
1.	I had confidence in the nurses looking after me			
2.	I had confidence in the doctors looking after me			
3.	I had confidence in the therapists looking after me			
4.	I was treated with respect and dignity whilst on the unit			
5.	I had enough privacy when discussing my condition, or when being examined or treated			
6.	I was given adequate information regarding my diagnosis/condition			
7.	I was involved as much as I wanted to be in the decisions regarding my care and therapy			

Figure 1b shows an example of responses using the adapted pictorial questionnaire (APQ)



A visual analogue scale is represented by the 3 pictures across the top of the board (Yes/Always, Sometimes, No/never). A question is represented by one or two picture cards which are given to the patient who places it under the appropriate scaled response as seen here.

Table 1: Demographics of the participants

	Patients with Aphasia **N=11**	**Patients with Cognitive Communication Disorders** **N=11**	**Patients with Dysarthria** **N=4**
Mean age in years (minimum-maximum; standard deviation)	44 (31-75; SD 16.8)	46 (18-56; SD 16.8)	45 (17-66; SD 17.8)
Male: female Ratio	4:7	8:3	2:2
Mean time since onset in months (minimum-maximum; standard deviation)	3.8 (1-13; SD 3.3)	3.1 (1-7; SD 2.7)	4.7 (1-7; SD 3.5)
Aetiology of brain injury (BI)	Stroke (n=11)	Stroke (n=5) Traumatic BI (n=6)	Stroke (n=5) Hypoxic BI (n=1)
Severity of impairment	**Auditory Comprehension** Severe (n=2) Moderate (n=7) Mild (n=2) **Written comprehension:** Severe (n=4) Moderate (n=6) Mild (n=1)	Severe (n=2) Moderate (n=1) Mild (n=8) **Auditory and Written Comprehension:** All patients had the linguistic capabilities to comprehend the spoken and written word at sentence level.	Severe (n=3) - anarthric Moderate (n=0) Mild (n=1) **Auditory and Written Comprehension:** Intact for all participants

Table 2: Results of whole group and sub-groups analysis across questionnaire format

Analysis Type	**Whole group results (n=26)** (number of questions with ≥ moderate agreement)	**PWA results (n=11)** (number of questions with ≥ moderate agreement)	**CCD results (n=11)** (number of questions with ≥ moderate agreement)
"Adapted pictorial" Time 1 versus Time2	14/21 (67%)	19/21 (91%)	13/21 (62%)
"Standard written" Time 1 versus Time 2	17/21 (81%)	18/21 (86%)	15/21 (67%)
"Adapted pictorial" versus "standard written" within-time	17/21 (81%)	18/21 (86%)	14/21 (67%)

Key to table:
PWA: Participants with aphasia
CCD: Participants with cognitive communication disorder
Numerator: number of questions with a kappa value of at least κ= 0.41 demonstrating greater than moderate agreement
Denominator: the total number of questions analysed (21)

Table 3: Test-Retest Reliability of the adapted pictorial questionnaire (APQ), by communication group

Question	PWA			CCD		
	Kappa Value	95% CI	p value	Kappa Value	Lower 95% CI	p value
1. I had confidence in the Nurses looking after me?	1.0	1.0, 1.0	0.001	1.0	1.0, 1.0	0.001
2. I had confidence in the Doctors looking after me?	1.0	1.0, 1.0	0.001	1.00	1.0, 1.0	0.001
3. I had confidence in the therapists looking after me?	1.0	1.0, 1.0	0.001	0.56	0.06, 1.0	0.04
4. I was treated with respect and dignity whilst on the unit?	1.0	1.0, 1.0	0.001	1.00	1.0, 1.0	0.001
5. I had enough privacy when discussing my condition or when being examined or treated?	0.62	0, 1.0	0.03	0.39	0, 1.0	0.2
6. I was given adequate information regarding my diagnosis/condition?	0.62	0, 1.0	0.03	0.81	0.47, 1.0	0.006
7. I was involved as much as I wanted to be in the decisions regarding my care and therapy?	0.74	0.28. 1.0	0.01	-0.17	0, 0.3	0.51
8. I was kept informed about my treatment/care and plans for discharge from the unit?	0.30	0.05, 0.54	0.12	0.12	0, 0.67	0.66
9. I was bothered about noise at night from other patients?	0.54	0.17, 0.91	0.02	0.36	0, 0.89	0.1
10. I was bothered about noise at night from staff?	0.58	0.20, 0.96	0.006	0.37	0, 0.83	0.1
11. I had a named key worker?	1.0	1.0, 1.0	0.001	0.62	0, 1.0	0.03
12. If a member of my family needed rehabilitation I would recommend that they come to this unit?	1.0	1.0, 1.0	0.001	0.63	0, 1.0	0.003
13. I achieved my goals for rehabilitation?	0.33	0.13, 0.52	0.01	-0.15	0 0.13	0.4
14. I was able to visit home at weekends?	0.56	0.06, 1.0	0.04	1.0	1.0, 1.0	0.002
15. I was able to talk to someone about my worries/fears?	0.44	0.06, 0.83	0.02	1.0	1.0, 1.0	0.002
16. I received appropriate pain relief when needed?	0.53	0.11, 0.95	0.006	0.59	0.11, 1.0	0.004
17. I was told about the purpose of medication?	0.56	0.06, 1.0	0.04	0.04	0 0.17	0.84
18. How clean was the hospital room or bay that you were in?	0.46	0.02, 0.89	0.02	0.78	0.18, 1.0	0.006
19. How clean were the toilets and bathrooms on the unit?	0.86	0.44, 1.0	0.001	0.60	0, 1.0	0.02
20. How would you rate the hospital food?	0.84	0.43, 1.0	0.001	0.51	0.11, 0.91	0.07
21. How would you rate the fabric/décor of the Unit?	0.48	0.07, 0.88	0.01	0.18	0, 0.57	0.19

Key to table:

▨ = Kappa values ≤0.4 in participants demonstrating less than moderate agreement and poor repeatability.

Table 4: Test-retest reliability of the standard written questionnaire (SWQ), by communication group

Question	PWA			CCD		
	Kappa Value	95% CI	p value	Kappa Value	Upper 95% CI	p value
1. I had confidence in the Nurses looking after me?	0.62	-0.05, 1.0	0.035	1.0	1.0, 1.0	0.002
2. I had confidence in the Doctors looking after me?	1.0	1.0, 1.0	0.002	1.0	1.0, 1.0	0.002
3. I had confidence in the therapists looking after me?	1.0	1.0, 1.0	0.002	0.36	-0.36, 1.0	0.284
4. I was treated with respect and dignity whilst on the unit?	1.0	1.0, 1.0	0.002	0.62	-0.05, 1.0	0.035
5. I had enough privacy when discussing my condition or when being examined or treated?	1.0	1.0, 1.0	0.003	0.61	-0.06, 1.0	0.047
6. I was given adequate information regarding my diagnosis/condition?	0.52	-0.05, 1.0	0.098	0.61	-0.06, 1.0	0.047
7. I was involved as much as I wanted to be in the decisions regarding my care and therapy?	1.0	1.0, 1.0	0.002	0.25	-0.07, 0.57	0.289
8. I was kept informed about my treatment/care and plans for discharge from the unit?	0.63	0.0, 1.0	0.005	0.40	-0.19, 0.99	0.134
9. I was bothered about noise at night from other patients?	0.83	0.53, 1.0	0.000	0.55	0.07, 1.0	0.032
10. I was bothered about noise at night from staff?	0.68	0.31, 1.0	0.001	0.63	-0.01, 1.0	0.008
11. I had a named key worker?	0.29	0.0, 0.58	0.035	0.55	0.07, 1.0	0.032
12. If a member of my family needed rehabilitation I would recommend that they come to this unit?	0.62	-0.05, 1.0	0.035	0.63	-0.01, 1.0	0.008
13. I achieved my goals for rehabilitation?	0.62	-0.05, 1.0	0.035	0.05	-0.25, 0.34	0.688
14. I was able to visit home at weekends?	0.35	-0.24, 0.94	0.260	0.61	-0.06, 1.0	0.047
15. I was able to talk to someone about my worries/fears?	0.80	0.44, 1.0	0.001	0.36	-0.36, 1.0	0.284
16. I received appropriate pain relief when needed?	0.62	-0.05, 1.0	0.035	1.0	1.00, 1.0	0.003
17. I was told about the purpose of medication?	0.62	-0.05, 1.0	0.035	0.36	-0.36, 1.0	0.284
18. How clean was the hospital room or bay that you were in?	1.0	0.38, 1.0	0.001	1.0	0.35, 1.0	0.001
19. How clean were the toilets and bathrooms on the unit?	0.74	0.14, 1.0	0.008	0.77	0.13, 1.0	0.009
20. How would you rate the hospital food?	0.53	0.11, 0.94	0.006	0.56	0.13, 0.99	0.006
21. How would you rate the fabric/décor of the Unit?	0.4	-0.21, 1.0	0.098	0.41	-0.13, 0.95	0.07

Key to table:

▨ = Kappa values ≤0.4 in participants demonstrating less than moderate agreement and poor repeatability.

Table 5: Agreement between the two questionnaire types (APQ and SWQ) by communication group

Question	PWA			CCD		
	Kappa Value	**95% CI**	**p value**	**Kappa Value**	**95% CI**	**p value**
1. I had confidence in the Nurses looking after me?	0.77	0.35, 1.0	0.001	1.0	1.0, 1.0	0.001
2. I had confidence in the Doctors looking after me?	1.0	1.0, 1.0	0.001	0.78	0.37, 1.0	0.001
3. I had confidence in the therapists looking after me?	1.0	1.0, 1.0	0.001	0.318	-0.27, 0.9	0.144
4. I was treated with respect and dignity whilst on the unit?	0.62	0.15, 1.0	0.002	0.61	0.12, 1.0	0.005
5. I had enough privacy when discussing my condition or when being examined or treated?	0.77	0.35, 1.0	0.001	0.26	-0.22, 0.74	0.101
6. I was given adequate information regarding my diagnosis/condition?	0.77	0.35, 1.0	0.001	0.64	0.37, 0.92	0.001
7. I was involved as much as I wanted to be in the decisions regarding my care and therapy?	0.5	0.05, 0.95	0.010	0.01	-0.29, 0.31	0.955
8. I was kept informed about my treatment/care and plans for discharge from the unit?	0.42	0.1, 0.74	0.008	0.76	0.48, 1.0	0.001
9. I was bothered about noise at night from other patients?	0.49	0.17, 0.82	0.004	0.64	0.35, 0.93	0.001
10. I was bothered about noise at night from staff?	0.77	0.53, 1.0	0.001	0.87	0.61, 1.0	0.001
11. I had a named key worker?	0.57	0.16, 0.97	0.001	0.2	-0.08, 0.48	0.216
12. If a member of my family needed rehabilitation I would recommend that they come to this unit?	0.64	0.01, 1.0	0.002	1.0	1.0, 1.0	0.001
13. I achieved my goals for rehabilitation?	0.17	-0.04, 0.38	0.071	0.16	-0.10, 0.43	0.254
14. I was able to visit home at weekends?	0.43	0.01, 0.85	0.052	0.83	0.5, 1.0	0.001
15. I was able to talk to someone about my worries/fears?	0.48	0.17, 0.78	0.001	0.38	-0.12, 0.87	0.094
16. I received appropriate pain relief when needed?	0.71	0.35, 1.0	0.001	0.74	0.43, 1.0	0.001
17. I was told about the purpose of medication?	0.48	-0.01, 0.98	0.028	0.18	-0.19, 0.55	0.328
18. How clean was the hospital room or bay that you were in?	0.25	-0.13, 0.63	0.098	0.53	0.13, 0.93	0.005
19. How clean were the toilets and bathrooms on the unit?	0.64	0.32, 0.95	0.001	0.46	0.06, 0.85	0.012
20. How would you rate the hospital food?	0.62	0.34, 0.9	0.001	0.8	0.5, 1.0	0.001
21. How would you rate the fabric/décor of the Unit?	0.38	0.15, 0.6	0.001	0.47	0.15, 0.78	0.002

Key to table: ▨ = Kappa values ≤0.4, demonstrating less than moderate agreement for PWA/CCD groups