Making a meaningful difference in aphasia rehabilitation

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Changing Clinicians’ Practices in Aphasia (CCLIPA)
Knowledge translation

Graham et al. 2006
Figure 5. Significant relationships between impairment, activity, participation, and the Well-being Scale, $N=30$. 

Figure 5. Significant relationships between impairment, activity, and participation and $N=30$, $r^2$. 

Finding a Focus
Measuring quality of life: Comparing family members’ and friends’ ratings with those of their aphasic partners

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Fig. 3. Average percentage of heavy and light verbs according to interview question in FWA.
Person-centred care in aphasia rehabilitation

Source: http://valuingpeople.org.au/sites/default/files/ValuingPeople%20Section%201_5.pdf
What matters to people with aphasia?

3 months (Grohn et al. 2012)
WAB AQ 27-99
- Needing to do things
- Social support and social relationships
- Rehabilitation
- Adaptation & adjustment
- Positive outlook

72 months (Brown et al. 2010)
WAB AQ 12-96
- Doing things
- Meaningful relationships
- Striving for a positive way of life
- Communication

41 months (Cruice et al. 2010)
WAB AQ 22-96
- Activities
- Verbal communication
- People
- Body functioning
- Stroke
- Mobility
- Positive personal outlook
- Independence
- Home
- Health
What matters to people with aphasia? continued

- Important aphasia outcomes (Wallace et al. 2016)
  - Improved *communication*
  - Increased *life participation*
  - Changed attitudes through increased awareness and education about aphasia
  - Recovered normality
  - Improved *physical* and *emotional wellbeing*
  - Improved health services

- Return pre-stroke life, *communication*, information, speech therapy and other health services, control and independence, dignity and respect, *social leisure and work*, altruism and contribution to society, and *physical function and health* (Worrall et al. 2011)
So, knowing this then…

Where and how are patients’ or clients’ values, priorities, concerns, or needs in these areas being identified in aphasia rehabilitation?

Goal setting practices?
Goal setting in stroke rehabilitation

- Patients are passive …. don’t control their goals, and professionals are prescriptive… yet professionals believe they are patient-centred (Rosewilliam et al. 2011)

- Acute: Rosewilliam et al. 2015; Foster et al. 2013
- Post-acute: Brown et al. 2013
- Inpatient: Levack et al. 2011; Barnard et al. 2010
- Chronic: Hersh et al. 2012; Worrall et al.
What makes a meaningful difference?

- **Formal documentation** of patients’ views
- **Explicit** methods, such as the COPM (Rosewilliam et al. 2011)
- **Patient-focused tools**
  - COPM, GAS, SIGA, Talking Mats (Stevens et al. 2013)
- **Routine recording** of patient priorities and preferences for treatment in patients’ medical records (Mangin et al. 2016)

...making patients’ values visible...
If not in goal setting, then where?

Where and how are patients’ or clients’ values, priorities, concerns, and needs, in these areas being identified in aphasia rehabilitation?

Assessment practices?
Clinicians’ assessment practices

- **<1%** assess QOL compared to **50+%** assess language (Vogel et al. 2010; N=174)
- **2%** QOL tools versus **46%** language tools (Simmons-Mackie et al. 2005; N=94; 336 assessment tools)
- **4%** assess QOL compared to **93%** assess language (Verna et al. 2009; N=70)

  ..... *Language assessments are unlikely to make patients’ values visible*....

- **39%** Psych state (Brumfitt 2006; N=173)
- **56%** PWB (Sekhon et al. 2015; N=111)
- **56%** QOL (Hilari et al. 2015; N=423; 10%+19%+27%)
Preference for informal QOL A

- 10% language tools (Verna et al. 2009) compared to 69%-100% psychosocial, QOL, and PWB (Brumfitt 2006; Hilari et al. 2015; Sekhon et al. 2015)

- Every single SLP informally assesses PWB
  - 96% observation
  - 95% PWA tells SLP
  - 91% clinical judgment
  - 89% Significant Other tells SLP
  - 82% emerges in team discussion
  - 66% identify during case history taking
  - 55% gut feeling (Sekhon et al. 2015)
Belief, practice & confidence mismatches

- SLPs strongly believe that PWA are at risk of poor PWB, affects rehabilitation outcomes, should be addressed BUT 44% don’t formally assess it

- Of the 56% who do, non-PWB tools are used (CAT DQ, CDP, SAQOL, AusTOMs)

- 60-74% disagree with feeling knowledgeable, confident & satisfied in assessing PWB (Sekhon et al. 2015; N=111)

- 74%-97% SLTs consider QOL main aim of aphasia rehabilitation, PWB is part of SLT role, and psychosocial issues ‘important–very important’ in client management (Brumfitt 2006; Hilari et al. 2015; Northcott et al. 2016)

- But only 31-42% SLTs are confident in addressing PWB & psychological needs (Northcott et al. 2016; Sekhon et al. 2015)
Person-centred care in aphasia rehabilitation

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Why QOL & QOL assessments?

- Multiple drivers for QOL
- Diminished in PWA; mood; relevant; rehabilitation aim
- Are a means of making clients’ values visible
- Legitimize the issues for clients with aphasia
  - by signaling priority/importance
- Legitimize the issues for clinicians
- Facilitate goal negotiation
- Enable more rigorous treatment planning, and for some, outcome measurement
Changing Clinicians’ Practices in Aphasia (CCLIPPA)
Research Team

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“... I’m actually quite nervous about coming along on Thursday, you know when you think ‘oh my God, I feel so out of my depth’ and there – like it’s, but that’s – that’s not a comfortable feeling for a kind of a clinician that’s been around for a little while and, you know, I think for me it’s probably all the more reason to come, erm but yeah, you know, when I think what do I think about quality of life, I found the questionnaire really stretched, you know, stretched me and made me feel uncomfortable, I think the workshop may do the same....” (P29)
"Changing the incidence of any behaviour of an individual, group or population involves changing one or more of the following: capability, opportunity, and motivation, relating to either the behaviour itself or behaviours that compete with or support it"  

(Michie et al. 2014)

"Changing behaviour is not easy, but is more effective if interventions are based on evidence-based principles of behaviour change"  

(Cane et al. 2012)
COM-B & Theoretical Domains Framework

**Capability**
- Psychological: Knowledge; Skills; Memory, Attention & Decision Processes; Behavioural Regulation; Innovation
- Physical: Skills

**Opportunity**
- Social: Social influences
- Physical: Environmental context & resources

**Motivation**
- Automatic: Emotions; Reinforcement
- Reflective: Beliefs about capabilities; Beliefs about consequences; Intentions; Goals
- Automatic & Reflective: Optimism; Social/Professional role and identity
Research aims

1. To explore clinicians’ views of QOL and QOL assessments, use of QOL assessments, and perceived barriers and facilitators

2. To assess the effectiveness of an educational intervention & subsequent implementation period on
   - Clinicians’ views of QOL and QOL assessments
   - Use of QOL assessments
   - Perceived ongoing/new barriers and facilitators
Supporting data

- Two studies (Cruice & ten Kate, in prep; Cruice, Isaksen, Jensen, Eggers Viberg & ten Kate, 2015*)
  - N=19, qualified SLT, 2yrs min(X=8.5yrs), rehab; Manchester & London
  - N=14; same criteria; X=8yrs exp.; all regions Denmark
- 49 item survey: Brumfitt 2006; Simmons-Mackie et al 2005; McKevitt et al 2003
- QOL: individual, life satisfaction, happiness, activities & participation; participation, independence, autonomy, meaningfulness
- Strong support for QOL in practice combined with feeling unprepared
- Limited self-reported knowledge, awareness, skills, confidence
- Emphasis on informal approaches, dialogue and questioning
- Barriers: time, knowledge and skills in QOL/Ax, QOL Ax; funders priorities
- Perceived future facilitators
  - knowledge, training, tools
  - team, staffing, time and acknowledgement of QOL by service
SLT Participants

- 35 F; 2 M
- 21-30yrs=15; 31-40yrs=12; 41+yrs=10
- Bachelor=17; PG Dip=16; Masters/PhD=4
- Mean: 6yrs experience
- 24 FT; 12 PT (majority 0.6-0.8)
- Band 5=8; Band 6=18; Band 7=10; Band 8=1
- NHS=27; Other (independent, social enterprise, voluntary, research)
- Community rehab=14; IP & ESD=4 each; Other
- London=12; South East=13; East Anglia=5; North and South West, East and West Midlands
- 5 PWA on caseload (range 0-16)
- W2 participants differed only in T1_Q36a SLT support
54 total enquiries
\( (W1=30, W2=24) \)

42 consent forms returned
\( (W1=24, W2=18) \)

37 completed PRE survey
\( (W1=20, W2=17) \)

37 attended workshops
\( (W1=20, W2=17) \)

36 completed POST survey
\( (W1=20, W2=16) \)

32 completed FOLLOW UP survey
\( (W1=19, W2=13) \)

5 withdrew before PRE survey
\( (W1=13, 20, 23, 24; W2=28) \)

1 did not complete POST survey
\( (W2=33) \) but did complete pre and follow up

5 did not complete FOLLOW UP survey
\( (W1=6; W2=25, 30, 37, 42) \)

37 analysed for demographics
32 analysed for research questions
\( (W1=19, W2=13) \)

Note #33 POST missing data was entered as the median of pre and follow up scores
CCLIPA Intervention Reporting

- Brief educational intervention (EPOC ‘educational meeting’)
- Theory/rationale
  - Knowledge to Action Framework (Graham et al. 2006)
  - Theoretical Domains Framework* (Cane, O’Connor, & Michie 2012)
  - Content; framing; practical hands-on viewing & discussion; application to current workplace; social learning/ group discussion
- Delivered as one day group workshop (5½hrs input + 2hrs breaks), face to face, based at university
- No pre-reading however T1 survey and a sub-sample pre-interviews; access to articles & assessments thereafter; T2 & T3 surveys; post-interview = reflection opportunity
- Not tailored although slightly more emphasis on completing domains supporting sheet in W2; no fidelity yet

TIDieR Hoffmann et al. 2014
CCLIPA Intervention continued

- Definition of QOL, policy/guidelines, evidence
- Foundations in QOL measurement
- Challenges and Pros & Cons
- Modifications: maintain/alter integrity
- Traffic light psychometric & purpose indicator
- 13 QOL (& related assessments) & approaches
- Scope: Broad, HRQOL, WB, Emotional, Social
- Cases, self practice, and clinical discussion/application
- Commitment to action plans
- Implementation period of 6 weeks

TIDieR Hoffmann et al. 2014
Data collection tool

- Anonymous: assigned numerical participant codes & completed through Qualtrics
- TDF structured questionnaire (14+1), devised as team, piloted
  - 16 TDF questions constant across time points
  - Some free text responses: QOL; Ax; Barriers & Facilitators; Action plans
- Quantitative 5-point scale of agreement (support, importance) with some categorical questions
- Interviews: sub-sample; role, priorities, decision-making, success – not presented here
Data analysis

- Analysed as a group, compared across time points
- Quantitative (EP)
  - Descriptive
  - Inferential
- Qualitative (MC)
  - Open coding content analysis
  - Subsequent framing using TDF where appropriate
- Small amount missing data
- Future analyses planned
Results: baseline

- Biased sample: ceiling on importance of
  - QOL in SLT management (BaCons)
  - QOL is part of SLT role (SPRI)
  - QOL is part of MDT role (SI)
- Social learning (obs. & discuss w colleagues) primary method of learning (89%), then reading (57%); training (in-house 21%, external 24%) (K,S)
- ECR: 65% engage org. & personal; 35% personal only
- ECR: Neutral/disagree service encourages them to address QOL
- SI: Neutral/disagree supported by SLT and MDT colleagues to use QOL Ax (even more ambivalent on latter)
- REINF: 19% have a process/protocol for QOL – mainly goal setting
- Emotions (can select more than 1 option)
  - Comfortable (38%), Calm (27%), Satisfied (14%)
  - Uncomfortable (27%), Anxious (27%), Confused (19%)
Order of reporting of results

- Qualitative
  - Understanding of QOL & how this changes across time
  - Use of QOL Ax & how this changes across time

- Quantitative: TDF
  - Views/ Beliefs about QOL, QOL Ax, and practice & how this changes across time

- Qualitative, but framed using TDF
  - Perceived facilitators & how this changes across time
  - Perceived barriers & how this changes across time
Understanding of QOL: Baseline

- Ability to engage/participate in/access to enjoyable, meaningful, and personally relevant activities
- Enjoyment, satisfaction and life fulfillment
- Individually determined: meaningful & motivating
- Communication
  - Relationships & interactions, activities
  - Negative impact of aphasia
  - Needing to communicate thoughts, wishes, needs, etc.
  - Carer support for communication
  - Communicating effectively
- Some mention of choice/control/autonomy (activities)
- Limited mention of psychological
Illustrative data: Baseline

- Ability to engage in enjoyable activities. Ability to express oneself meaningfully to friends and family (P01)

- That the person with aphasia can still participate in and enjoy a life that they deem to be meaningful and include many of the activities and interactions that they were involved in prior to their onset of aphasia (P35)
Understanding of QOL: Post-intervention

- **Heightened** emphasis on the personal and qualified (meaningful, fulfilling, enjoyable, satisfying life), and wellbeing

- **NEW**
  - **Broad**, multifactorial, influenced by factors/ predictors (e.g. health, mood)
  - **Domain** structure (activities, social participation, communication, health/ physical, mood/ psych state, independence, relationships and interaction)
  - Communication **connected** to QOL
  - Small indication: QOL relevant in rehabilitation process
Reflection: changed or affirmed?

- Given me a broader idea of what quality of life is as well as options for measuring it (P22)

- It has given me a more in-depth understanding of how complex this is, but also helped me think about how my skills as a therapist will help me to unpick these issues and work through them. I think broadly I understood what QoL meant but after today I have a better idea of the many different contributing factors towards it and also how correlated these may be (P08)
Understanding of QOL: Post-implementation

- **Continued** strong emphasis on
  - Individual
  - fulfillment, enjoyment, satisfaction, meaning, happiness
- **Continued** multifactorial and domain structure
  - Participation in activities, ability activities, communication and *relationship to QOL areas*, relationships, mood
- **Increased** emphasis on **health** (physical, emotional), wellbeing
- **NEW**: priority and value of QOL to SLT and SLT role
QOL in aphasia is a central part of my involvement with clients. Working on one area can also impact others, e.g., if I work on communication with a client it can affect their level of activity as they may feel more confident to communicate when out and about. I consider it when meeting clients for the first time and during the assessment process and also in relation to treatment as it helps with goal planning (P19).

QoL is different from everyone and in the context of our clients, is their perspective of what will enhance their life whether it be better communication, more successful interactions, involvement in more activities or experiences, better health etc. It is their QoL that we must take into account when we are goal setting with our clients, and is something we should think about how we can measure before and after therapy to assess the impact of our interventions (P35).
Baseline: Awareness of Ax

- LPAA, AFROM, ICF
- Patient-centred goal setting: TM, EKOS, COPM, SFBT
- CDP [12], CAT DQ [11], COAST [6], AIQ, CCRSA, CRUI
- SAQOL [16], SSQOL, ALA, SWLS, VASES [7], DISCS

Baseline: Use of Ax

- 40% only informal
- 35% informal & formal Ax
- 25% only formal
- COAST [7], CDP [5], CAT DQ [5], VASES [4], TOMS [3], ALA [3], AIQ [3]
- SAQOL, HADS, PHQ-9, GAD-7, BASDEC, NEADLI [1]

Baseline: Decision-making

- Informal valued
- Formal only if need identified
- Severity aphasia
- Availability Ax
- Usefulness, psychometrics, accessibility
- Seeking advice
- Lack knowledge tools & experience
Implementation Plans

- **Intended:**
  - Many (56%) – present/feedback information & resources to others
  - Some (22%) – discuss with colleagues, trial, then incorporate into routine assessment
  - Large minority (48%) – try Ax with current and new clients in own practice, try out self & reflect
    - Use Ax on next initial assessment; use 1 Ax with every patient; use with 2 clients; adapt the CRUI for goal setting; trial with severe patients; use with all aphasic patients
  - Some (30%) – access resources, create toolkit, read references

- **Actual:** Used Ax, fed back, still intending to feedback & use

- **Barriers:** time, insufficient opportunity to implement with clients, no opportunity for team feedback, Dropbox access difficulties
Post-Int.: Awareness of Ax

- Named 2-15 Ax
- Majority: 7+ Ax
- AIQ, QOL Questions, Social network map, EQ5D, SAQOL, COOP, CCRSA, WHOQOL, SADQ, CRUI
- DISCS, SWLS, CIQ (less than 10 times)

Post-Int.: Intention to use

- 50-70%: AIQ, Social network map, QOL Questions, CCRSA
- 25-50%: COOP, CRUI, SAQOL, SADQ, EQ5D
- Share & discuss with MDT (COOP, EQ5D, mood)
- Ease of integration, relevance to service provision/outcomes, visual accessible nature

Post-Int.: Decision-making

- Severity aphasia
- Relevance Ax to client: concerns & priorities
- Ax: scope, adaptability, psychometrics, length, efficiency
- Purpose of Ax (OM, GS, EP)
- Setting/ pathway
Intend to use quality of life assessments more consistently as part of my standard practice with all clients, whilst suspending judgments about what may and may not work to some extent until after have attempted some assessments as appropriate (P10)

I want to begin to consider measuring QoL as an option in my day to day battery. Eventually, I want to integrate some QoL options into my standard practice and possibly even look at liaising with the MDT about possible collaborative use in assessment and goal setting (P14)
Post-Imp.: Awareness of Ax
- Named 0/3-14 Ax
- Mode: 5 Ax
- 50%: AIQ, SAQOL, Social network map, COOP
- 33%: QOL Questions, EQ5D, CCRSA, WHOQOL, SADQ, DISCS, CRUI
- VASES, CIQ, SWLS, SOCACT, CDP

Post-Imp.: Ax used
- 78% used 1-4 Ax
- Social network map [11], SAQOL [7], AIQ [6], QOL Questions [5], EQ5D [5], CCRSA [5]
- VASES, COOP, ALA [2]
- VAMS, SADQ, PHQ-9, GAD-7, DISCS [1]
- CRUI, COAST, CDP, COPM [1]

Post-Imp.: Decision-making
- Language, cognition+
- Mood, motivation, interests/needs
- Purpose of Ax & scope
- Stage of care/setting
- Length/speed/ease administration
- Ax: psychometrics, availability, adaptability
Quant Results: Baseline

Legend:
- Disagree
- Neutral/disagree
- Neutral
- Agree
- Strongly agree

**Capability**
- Psychological: Knowledge, Skills, Innovation*

**Opportunity**
- Social: Social influences
- Physical: Environmental context & resources

**Motivation**
- Automatic: Emotions & Reinforcement
- Reflective: Beliefs about capabilities & about consequences, Intentions, Goals
- Automatic & Reflective: Optimism, Social/Professional role and identity
Quant Results: Post-intervention

Legend:
- Disagree
- Neutral/disagree
- Neutral
- Agree
- Strongly agree

Capability
- Psychological: Knowledge, Skills, Innovation

Opportunity
- Social: Social influences
- Physical: Environmental context & resources

Motivation
- Automatic: Emotions
- Reflective: Beliefs about capabilities & about consequences, Intentions, Goals
- Automatic & Reflective: Optimism, Social/Professional role and identity
Results: Post-implementation period

- **Capability**
  - Psychological: Knowledge, Skills, Innovation*

- **Opportunity**
  - Social: Social influences
  - Physical: Environmental context & resources

- **Motivation**
  - Automatic: Emotions
  - Reflective: Beliefs about capabilities & about consequences, Intentions, Goals
  - Automatic & Reflective: Optimism, Social/Professional role and identity

**Legend:**
- Disagree
- Neutral/disagree
- Neutral
- Agree
- Strongly agree
Slides on Facilitators and Barriers at each time point removed as not covered during presentation
Research aim 1: findings synthesis

- QOL: individually determined, personal meaningful activities and participation; communication separate
- Informal: Formal – 75 (40+35):60 (35+25)
- More aware & use of comm. Ax than QOL Ax
- Awareness ≠ usage
- Critical/? appropriate QOL assessments
- Barriers: limited knowledge, skills, comfortable, confidence; lack QOL resources; time, hospital setting, organizational priorities, rehab-QOL fit, client functioning and motivation
- Facilitators: optimistic, belief in QOL and SLT role, team, community setting, patient-centred goal setting, knowledge client, own SLT skills
Research aim 2: findings synthesis

- Broad, multifactorial, domain structure to QOL with communication connected to QOL; health, priority/value to SLT and SLT role
- Increased awareness; 25-70% intend to use various Ax; identified Ax for MDT; privileged Ax; integrated differentiated decision making (client/Ax and purpose); remembered range; 78% used 1 Ax; 6 Ax mostly used; differentiated DM with further consideration mood
- Sig. improved & retained Knowledge, Skills, Resources, Emotions, Beliefs about Capabilities/Consequences; decrease in Intentions (sig.), Optimism, Resources
- Facilitators: new Knowledge, Confidence Resources; implementation improves Motivation further (BaCon, SPRI)
- Barriers: Environmental Context; Social Influences, Belief about Consequences; persistent but lessened in emphasis
Discussion

- Beliefs - Knowledge & Skills mismatch (Brumfitt 2006; Cruice & ten Kate in prep; Cruice et al. 2015; Hilari et al. 2015; Northcott et al. 2016; Sekhon et al. 2015)

Motivation – Capability gap
- Seemingly *more* use of formal QOL Ax (60%) ✓
- Assessing communication ✓
- Activities & participation? Mood?
- Numerous Environmental Context &
- Resources barriers

Hoffmann et al. 2010
Discussion continued

- CCLIPA effective at producing knowledgeable and resourced clinicians who now make informed decisions and commence using QOL assessments, considering it their role
  - Improves Capability (mostly Knowledge) ✓
  - Redresses Opportunity (almost entirely Physical: Resources) ✓
  - Enhances Motivation even further, especially noticeable post-implementation

- CCLIPA does not address other influential Opportunity: Environmental Context & Resources and Social Influences domains
  - Time
  - Service provision & priorities
  - SLT/MDT knowledge, priorities, resistance, support

- Surveys (& interviews) potentially transformational?
Future directions & considerations

- Analysis and integration of interview findings
- Investigation of active ingredients using BCT

Next stage intervention development & evaluation:

- Extending intervention (monitor & sustain knowledge, evaluate outcomes combined with EPOC implementation)
- Expanding intervention content for SLTs (QOL-goal-treat; Skills)
- Differentiating for ‘non-believers’ SLTs
- Online delivery…?
- Elevating intervention to team/service level…?
- Feasibility RCT comparing CCLIPA to standard practice (Educational Materials: journal club)…?
Having completed the workshop, it has highlighted the importance of addressing QOL in more depth with patients with aphasia. It is always something I consider, but I can now see the value in using a QOL tool in a more formal way. It can be a powerful way of legitimising what is important to an individual, and showing that person that you feel it is important too.