Measuring outcomes
Making a difference

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Current state of (reported) practice

SLTs/SLPs in aphasia
- Practise eclectically integrating approaches (philosophical & trx)
- Infrequently assess or record outcomes at broader life impact, participation and quality of life levels (variation depends on country)
- And predominantly use informal methods to do this
  (Brumfitt, 2006; Simmons-Mackie et al., 2005; Verna et al., 2009)

Drivers for change: personal, service, professional and international
Growing evidence base in qualitative accounts of early & chronic exp.
Growing evidence base in new or modified measures
Early experiences of living successfully with aphasia

People with early onset aphasia (N = 15, mean age 66yrs, stroke within past 3 months, mean WAB AQ 73 range 27-99) described:

• **Needing to do things** (homework, sense of being in control, lead to independence, meaning and purpose)

• **Social support and social relationships** (friends and family, other patients)

• **Rehabilitation** (care, recovery, relationships*, information, actual therapy*, needing to make relevant to everyday things)

• **Adaptation and adjustment** (taking time, strategies)

• **Positive outlook** (optimism, hope, determination, gratitude)

Living successfully with chronic aphasia

People with chronic aphasia (N = 25, aged 38-86 yrs, mean 72 months TPO, mean WAB AQ 77 range 12-96) described:

- **Doing things** (in relation to home, hobbies/leisure, and work/education): as providing sense of independence, ability/achievement, purpose, pleasure and wellbeing, stimulation for brain

- **Meaningful relationships**: support, acceptance and understanding, social companionship, caring for others

- **Striving for a positive way of life**: positive attitude and perseverance, acceptance, moving ahead, focusing on improvements, appreciation, trying new things/adapt, sense of humour, takes time

- **Communication**: verbal communication, embedded in above themes, communication strategies

Brown, Kyla et al. (2010). Snapshots of success paper in *Aphasiology*
http://www.tandfonline.com/doi/abs/10.1080/02687031003755429#.UnnilhZCgy4
Quality of life with chronic aphasia

People with chronic aphasia (N = 30, aged 57-88yrs, mean 41 months TPO, mean WAB AQ 74 range 22-96) described (Cruice et al., 2010):
People’s goals post-stroke with aphasia

People with chronic aphasia (N = 50, mean age 64yrs, mean 55 months TPO, mean WAB AQ 70) described goals relating to:

- **Return to pre-stroke life**
- **Communication** (needs & social; linked to real life; emotions)
- **Information** (aphasia, stroke, trx)
- **Speech therapy** (relevant, longer, understanding)
- **Control and independence** (own home, decision making)
- **Dignity and respect**
- **Social, leisure and work**
- **Altruism & contribution to society**
- **Physical function & health**

Worrall et al. (2011) What PWA want in *Aphasiology*

QOL Questions *(EP, SG)*

- Multidimensional & generic individualized approach

(1) (a) How would you describe the quality of your life?
   (b) And why do you say that?
(2) What things give your life quality?
(3) What things take quality away from your life?
(4) What would make the quality of your life better?
(5) What would make the quality of your life worse? *(Farquhar, 1995)*
(6) Does communication have an impact on the quality of your life?
   If yes, then how? *(Cruice, Hill, Worrall & Hickson, 2010)*

- Funnel: life -> participation -> communication & activity -> functioning
- Combine with Talking Mats approach
AIQ (MO, SG)

Aphasia Impact Questionnaire (AIQ: Swinburn)

• Contact Alex Stirling at Connect alexstirling@ukconnect.org
• Will be available to download for £25 from Connect’s website soon
• Multidimensional & condition-specific measure
  – 19 items with reference to the CDP
  – Communication, participation, emotions (past week time frame)
  – Graphic-supported response scale
• Robust psychometrics (awaiting publication)
• Qualitative study supports quantitative findings
  – Cruice & Swinburn (2012) & Swinburn et al. (2013)
This week...

How **easy** was it for you to **talk** to a **stranger**?
CCRSA (MO, SG)

Communication Confidence Rating Scale for Aphasia (CCRSA: Cherney & Babbitt)

- Available free from lcherney@ric.org or ebabbitt@ric.org
- Unidimensional & presumed condition-specific measure
- 10 items drawn from the ASHA QCL scale
  - Modified with self-efficacy concept from stuttering literature
  - Reduced number of items (final version 10 items)
  - Modified response format (0-100 VAS with numerical and word anchors)
RIC – CCRSA Communication Confidence Rating Scale for Aphasia
Cherney, L. R. & Babbitt, E. M.

6. How confident do you feel that people understand you when you talk?

0  10  20  30  40  50  60  70  80  90  100
Not Confident               Moderately Confident               Very Confident

7. How confident do you feel that people include you in conversations?

0  10  20  30  40  50  60  70  80  90  100
Not Confident               Moderately Confident               Very Confident
Clinical case example: be research-inspired!

- Single case study of strategy-based reading treatment
- Reading ability (GORT-4), Reading Confidence and Emotions Questionnaire (RCEQ) (EP, SG, MO), & Exit interview (MO, CI)
- Modified the unstandardized Communication Readiness and Use Index (CRUI: Lyon et al., 1997)
  - expanded by separating items
  - added emotions
  - modified response scale
- Significant gains in formal standardized measure (GORT-4) and unstandardized measure (RCEQ) and clearly positive outcomes as identified in exit interview

See Cocks, Pritchard, Cornish, Thompson, & Cruice (2013)
Exit interview (CI)

- How have you found coming to the reading clinic?
- Have you noticed any changes with your reading or your communication since you started coming?
- How do you feel you’ve gone with your goals?
- What did you like, or what was good, about the therapy?
- Was there anything about the therapy that you didn’t like or that could have been better?
- Do you have future goals for your reading? If so, what are they?
- Is there anything else you wanted to comment on that we haven’t covered?
“for two years… I only read one book and in the last six months I’ve read at least four books and I’ve tried at least half a dozen other books so… the change I’ve noticed is that my confidence and my determination is there and the belief is there erm and I also think about how I read, I don’t just try to do it because that failed. So I’m actually thinking about what I read, how I read, when I read it and I was upset by having to do that at first but I’m not now and I enjoy it”
Looking further afield for measures (MO)

- 8 week speech group for 5 clients (2MND, 1 PD, 1 PSP, 1 RCVA) to provide conversational interaction opportunities, in a supportive participation-focused environment (Cruice, Winkworth et al., 2003)
- **Key**: joint working, risk taking, team working
- **Personal Report of Communication Apprehension** (PRCA-24: McCroskey) - feelings about communicating with other people
  - “Generally, I am comfortable while participating in group discussions”
  - “While participating in a conversation with a new acquaintance, I feel very nervous”
  - Available online
- Achieved reduced communication apprehension (also compared to norm) for clients, and variable emotional health outcomes (GDS) (+ weekly self-ratings of talking & listening; post-group reflections)
Collaborating for research in practice

Service evaluation of communication and QOL outcomes in ESD stroke services (Susannah Hinchliff, 2013) (MO)
- WAB-R, BOSS CD, CIQ, EQ5D & HIFAM

Impact of project-based therapy with an explicit participation focus on participation, activity, language and QOL for a single case study of a gentleman with aphasia (Helen Day, 2013) (MO)
- COOP Charts, POWERS, SWLS & HIFAM

Preliminary psychometrics on quantitative measures of communicative and social activities (Sukhpreet Aujla, 2013) (EP & SG)
- COMACT & SOCACT

Inpatients’ perceptions and experiences of goal setting in adult neuro-rehabilitation (Aoife Hargadon, 2013) (EP & SG)
- Topic guide supported interviews
Consolidating practice knowledge

- Consensus approaches to consolidating expert practice knowledge
- Popular and publishable!
- Nominal Group Technique (NGT) & Delphi Method
- NGT
  * Selecting the question & identifying participants
    - Silent generation of ideas
    - Round robin
    - Discussion & checking
    - Ranking
- Time & facilitator are key
- Benefits – learn from each other & data is immediately available
NGT examples

“What constitutes good goal setting practice?” with Rachel Barnard and adult clinical colleagues across London (Cruice & Barnard, 2010) (SG)

“What constitutes a good outcome for patients and families leaving your service?” with Homerton University Hospital SLT Team (MO)

“What aspects are important for the SLT to address when working with people with semantic dementia and their families?” with Jacqueline Kindell (NIHR PhD student) and Dr Sage, University of Manchester (EP)

2014 project: Cruice & Sage England data collection site for ROMA by Sarah Wallace (PhD student in Australia) with Worrall, Le Dorze & Rose (inspired by COMET http://www.comet-initiative.org) (MO)
Summing up

• Consider asking about broad life quality issues
• Follow up with specific measures of impact and confidence
• Use research as a guide and for inspiration in developing own questions
• Prioritize and systematize the exit interview
• Look further afield for measures and inspiration
• Conduct research collaboratively
• Capture expert practice and create new knowledge

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References


* Aujla, Day, Hargadon, & Hinchliff are unpublished MSc Human Communication dissertations, which are in the process of being submitted for peer-reviewed publication.
References


