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Improving the quality of life of people with aphasia: what can we do about it?

ANCDS, Denver Colorado, 2015

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Thank you

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- External Collaborators: Connect, Uni of Nottingham, Kings CTU
- Funders: Dunhill Medical Trust, Consortium for Healthcare Research, Stroke Association, BAS, City RSF
- City University LCS students
- Clinical teams: St Mary's NHS Trust; Royal Free NHS Trust; Community SLT in Lambeth, Southwark & Lewisham; SLT team Queen Mary's Sidcup; Stroke Association Community Stroke Groups
- People with aphasia who took part
- Thales aphasia project for funding visit
- ANCDS for invitation

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Outline

- Background
  - What is Quality of Life (QoL) and Health-Related Quality of Life (HRQL)?
  - Why focus on QoL & HRQL with people with aphasia?
- What factors affect QoL & HRQL in aphasia?
- What SLP therapies can lead to QoL & HRQL benefits?
- SLPs views and practices on providing psychosocial support for people with aphasia
- Schemes and therapies to support aspects of QoL & HRQL: work at City University London

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What is Quality of Life (QoL) and Health-Related Quality of Life (HRQL)?

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World Health Organisation (WHO) definition of QoL

[…] an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in complex ways by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment.

(WHOQOL Group, 1995, p. 1405)

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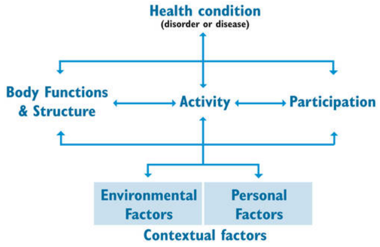
Health related QoL (HRQL)

- HRQL reflects the impact of a health state on a person's ability to lead a fulfilling life.
- It incorporates the individual's subjective evaluation of his/her functioning in:
  - physical,
  - mental/emotional,
  - family and social domains

Series of papers in *Quality of Life Research (1993) vol 2*

WHO ICF



Modelling

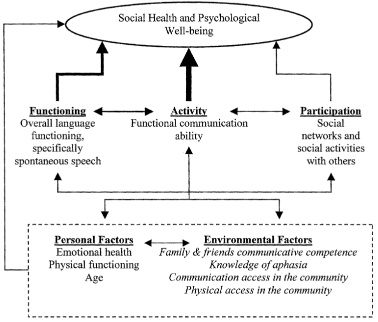
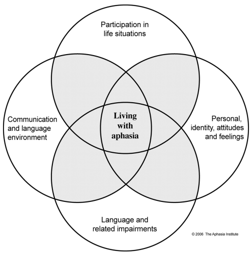


Figure 6. A new communication-related quality of life (CRQOL) model for people with aphasia.

Cruice et al. (2003) *Aphasiology*

Living with Aphasia: Framework for Outcome Measurement (A-FROM)



Kagan et al. (2008)

Distinction between ICF and QoL & HRQL

ICF

- Activity: *'Follows simple verbal commands'* ASHA-FACS
- Participation: *'Are you doing as much as you want?'* ALA

QoL & HRQL

- *'How much trouble did you have understanding what other people say?* SAQOL-39
- *'How satisfied are you with your ability to perform your daily activities?'* WHOQOL-BREF

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Why focus on QoL & HRQL with people with aphasia?

Profound impact of aphasia

PROMs

Professional Guidelines

People's priorities

Aphasia has a profound impact on people's lives

- A population-based study of people living in long-term care facilities in Canada (n = 66,193) compared the impact of 60 diseases and 15 conditions on caregiver-assessed preference-based quality of life.
- Adjusting for age, sex, and other diagnoses
- Aphasia exhibited the largest negative relationship to preference-based quality of life followed by cancer and Alzheimer's disease.

(Lam & Wodchis, 2010, *Medical Care*)

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Aphasia has a profound impact on people's lives

- Emotional well being affected and increased incidence of depression (Hilari, 2011; Kauhanen et al., 2000)
- Impacts on long-term outcome; reduces effects of rehab; higher mortality rates (Ferro et al., 2009; Hackett et al., 2008)
- Reduced social activities, loss of contact with friends and wider network (Cruice et al., 2006; Northcott & Hilari, 2011)
- In the elderly: friendships => higher well being; enhanced survival (Pinquart & Sorensen, 2000; Giles et al., 2005)

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Patient Reported Outcome Measures (PROMs)

- Better understand and measure the impact of disease on the client's life as a whole
- Incorporate the client's perspective in clinical decision-making

See in USA www.nihpromis.org and in UK http://www.hscic.gov.uk/proms

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Professional Guidelines

- American Speech and Hearing Association (ASHA) scope of practice document sets as the overall objective of SLP services to optimize individuals' ability to communicate and swallow, thereby improving QoL
- In the UK, the Stroke Clinical Guidelines of the Royal College of Physicians (RCP) set as key aims of stroke and aphasia rehabilitation: to maximise the patient's sense of well being and QoL
- Speech Pathology Australia Association (SPAA) scope of practice statement: one of the many possible outcomes to be achieved through the provision of speech pathology services is the improvement in general health, well-being, and QoL

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People's own priorities

Stroke

- Top 10 priorities in stroke research include: how to help people and families cope with speech problems; helping people to come to terms with the long term consequences of stroke; and improving confidence after stroke.

(Pollock et al., 2014)

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What factors affect QoL & HRQL in aphasia?

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People with aphasia vs. controls

- People with aphasia: worse QoL
- Differences mainly in three domains:
  - Level of independence
  - Social relationships
  - Access to environment

(Ross & Wertz, 2003, *Aphasiology*)

People with aphasia vs. people with stroke

- Cohort of people with stroke (n=87) followed up from hospital to 6 months (n=71)

People with aphasia:

- perform less social and leisure activities
- and have worse quality of life than people without aphasia post-stroke
  - even when no differences in emotional distress, basic ADL and social support

(Hilari, 2011, *Disability and Rehabilitation*)

Factors affecting QoL & HRQL in aphasia

Systematic review of quantitative (11 studies, n = 742) and qualitative studies (3 studies, n = 98): poorer quality of life in people with aphasia predicted by

- *emotional distress/depression*
- *severity of aphasia and communication disability*
- other medical problems
- activity & participation limitations
- aspects of social network and support

(Hilari et al., 2012, *APMR)*

Living successfully with aphasia

A meta-analysis of qualitative studies identified seven overarching themes related to living successfully with aphasia. These were:

- participation
- meaningful relationships
- support
- communication
- positivity
- independence and autonomy, and
- seeing living successfully with aphasia as a journey over time

(Brown et al., 2012, *IJSLP*)

Summary of key factors

Emotional Distress / Depression

- Rates of depression:
  - 31% for all stroke survivors (Hackett et al., 2014)
  - 62% for those with aphasia (Kauhanen et al., 2000)
- Predictors in aphasia
  - Loneliness and low satisfaction with social network (Hilari et al., 2011)

Communication

- Aphasia blog talk project
  - Consistent thread running through all blogs; affecting interactions with all aspects of one's network
  - ✗ Expressing needs, thoughts, ideas; ✗ conversations; ✗ humour
  - Profound impact on
    - ✗ Activities and participation
    - ✗ family and social relationships

Fotiadou, Northcott, Chatzidaki & Hilari (2014) *Aphasiology*

Social relationships

- People with aphasia (n=83) lose their friends
  - Most (64%) saw their friends less
  - Mean number of friends = 3
  - 30% no friends
  - For women, size of network was associated with quality of life
- Loss of friends is a problem in stroke more generally (in depth interviews, n=29), but PwA
  - Most hurtful responses by others
  - More likely to feel abandoned, deserted
  - At risk of losing entire social network

Hilari & Northcott (2006), *Aphasiology;* Northcott & Hilari (2011) *IJLCD*

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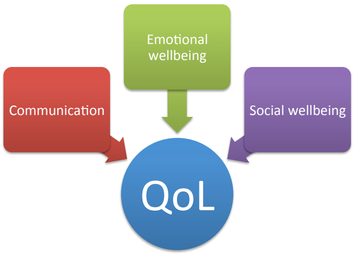
So… to address QoL / HRQL in aphasia



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What SLP therapies can lead to QoL & HRQL benefits?

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Evidence from systematic reviews?

- Limited to non-existent because…
- QoL / HRQL is **RARELY INCLUDED AS AN OUTCOME** in aphasia studies.
  - Simmons-Mackie et al., 2010 on conversation partner training
  - Cochrane review of aphasia therapy (Brady et al., 2012)

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Specific therapy approaches and interventions to improve QoL and HRQL?

Promising evidence for:

- Group therapy in terms of psychosocial benefits (Elman, 2007; Ross et al., 2006) and improved social participation and social connection compared with controls (Vickers, 2010)
- Impairment-based therapy for word finding difficulties, when targeted around an individual's interests (Best et al., 2008)
- Intensive comprehensive aphasia programs (Rodriguez et al., 2013)
- Models of community service provision (e.g., Fink et al., 2000; van der Gaag et al., 2005; Legg et al., 2007; Mumby and Whitworth, 2012)

** But need more evidence with larger sample sizes and appropriate controls

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Current RCTs of aphasia therapy incorporating QoL / HRQL outcomes

- Nouwens F, et al.: Rotterdam Aphasia Therapy Study (RA [illegible] acy of intensive cognitive-linguistic therapy in the acute stage [illegible] gn of a randomised controlled trial. Trials 2013; 14: 24.
- Baumgaertner et al.: FCET2EC (From controlled experim ntal trial to= 2 everyday communication): How effective is intensive integrative therapy for stroke-induced chronic aphasia under routine clinical conditi ns? [illegible] dy protocol for a randomized controlled trial. Trials 2013;14: [illegible]
- Godecke et al.: A comparison of aphas [illegible] utcomes before and after a Very Early Rehabilitation programme [illegible] e. International Journal of Language & Communication Disor [illegible] 9: 149-161.
- Thales aphasia project: Efstratiadou et al. on effectiveness of elaborated Semantic Features Analysis (one to one vs. group therapy)

EQ-5D

SAQOL-39

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Speech and Language Therapists views and practices on psychosocial support

UK survey (n=214)

Northcott, Simpson & Hilari (in prep)

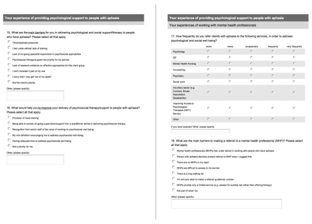
Methods

- Anonymous Online survey (SurveyMonkey)
- SLPs working with aphasia (BAS members, Clinical Excellence Networks, snowballing)
- Ethics approval:

School of Health Sciences,

Research Ethics Committee,

City University London.



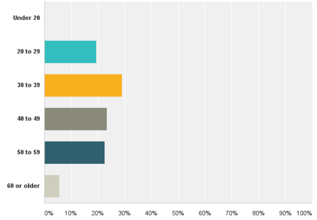
Survey

- 22-item questionnaire
- Responses: open ended, multiple choice, 5 point rating scales

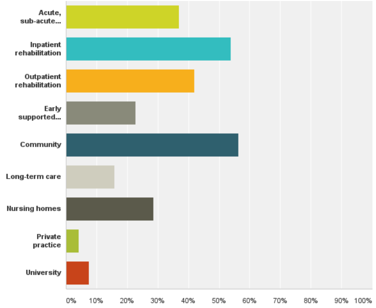
1. Background information: demographics; SLPs' workplace; experience of working with people with aphasia
2. SLPs' training in delivering psychosocial therapy or support
3. SLP's views on psychological distress in aphasia: extent of problem
4. SLPs role & psychosocial approaches currently used
5. Barriers and enablers to SLPs providing psychosocial therapy / support
6. SLPs' experiences of working with mental health professionals (MHPs)
7. Two optional free text responses at the end: describe experiences of working with MHPs, and giving SLPs the option to add any further comments on addressing the psychosocial needs of PWA.

Participant characteristics (n=214)

- The majority of participants were female (96%), white (86%), and had been working as an SLT for more than ten years (56%).
- The majority agreed /strongly agreed that they were knowledgeable (93%), confident (92%) and experienced (89%) in their work with people with aphasia.
- Age



Workplace setting



Training in delivering psychosocial therapy or support

- Most likely to have received training in counselling, with 67% having received at least some training, and 25% having gone on either a short course or studied for a certificate/diploma.
- 66% had received some training in social approaches (e.g. facilitating peer support, working with family) with 19% having received more than one day of training.
- Some training (majority less than a day) in solution focused brief therapy (45%), cognitive behavioural therapy (29%), motivational interviewing (15%), and narrative therapy (20%).

Proportion of PwA experiencing psychological distress

- 77% of respondents indicated at least 50% clients were experiencing psychological difficulties
- 50% of respondents indicated over 70%
- 33% of respondents indicated over 80%.

'Everyone's psychological state is affected by stroke, it seems inevitable'

'aphasia is such a massive life change plus threat to identity'

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Psychosocial approaches currently used by SLTs

They used frequently or very frequently

- Supportive listening: 100%
- Selecting holistic goals: 88%
- Working on social support e.g. facilitating peer support or selecting social goals: 83%
- Work with family / significant others: 81%

- Opportunities for clients to share their stroke or life story: 43%
- Used specific psychotherapeutic techniques, such as CBT or SFBT: 11%

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SLP role

The majority of respondents agreed/strongly agreed that the following areas were part of an SLP's role

- Client's confidence (99%)
- Participation/ engagement in social activities (99%)
- Social support/relationships (97%)
- Psychological well-being (93%)

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How SLP's feel about addressing psychological and social needs of PwA

- More confident addressing social needs (72% agree or strongly agree)
- Than psychological needs (42% agree or strongly agree).
- Similarly they feel more knowledgeable and more experienced addressing the social than the psychological needs.

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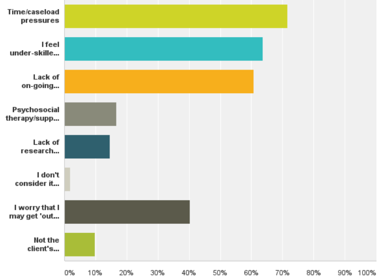
Main barriers in delivering psychological and social support / therapy to PwA



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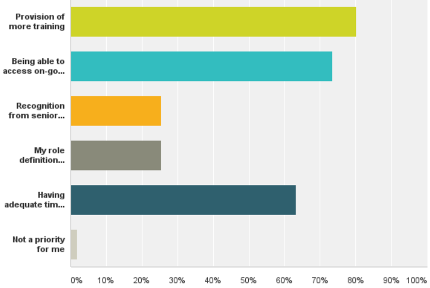
What would help improve your delivery of psychological and social support / therapy to PwA



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Referring on to other services to address psychological and social well-being

- SLPs were most likely to refer to voluntary sector organisations in order to address to the psychosocial well-being of clients (85% frequently/ very frequently)
- Psychology services (38% frequently/ very frequently)
- Social services (31% frequently/ very frequently)
- GP (17% frequently/ very frequently)
- Counselling (14% frequently/ very frequently).

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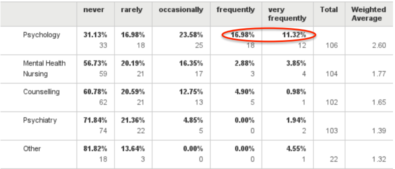
Barriers to referring to MHPs

- MHPs feeling underskilled when working with PWA (44%)
- MHPs being difficult to access (41%)
- MHPs providing only a limited service (37%)
- Referral guidelines being unclear (34%).
- SLPs did not commonly work collaboratively with MHPs



	never	rarely	occasionally	frequently	very frequently	Total	Weighted Average
Psychology	31.13% 33	16.98% 18	23.58% 25	16.98% 18	11.32% 12	106	2.60
Mental Health Nursing	56.73% 59	20.19% 21	16.35% 17	2.88% 3	3.85% 4	104	1.77
Counselling	60.78% 62	20.59% 21	12.75% 13	4.90% 5	0.98% 1	102	1.65
Psychiatry	71.84% 74	21.36% 22	4.85% 5	0.00% 0	1.94% 2	103	1.39
Other	81.82% 18	13.64% 3	0.00% 0	0.00% 0	4.55% 1	22	1.32

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Summary

- SLPs consider that the majority of their clients are experiencing psychological difficulties; they also mostly agree that the psychological well-being of clients is part of the SLT role (93%)
- Only 43% are confident in addressing the psychological needs of their clients
- Main barriers: time pressures (72%); feeling under-skilled (64%); lack of ongoing specialist supervision (61%). Training and ongoing supervision and support would help
- SLPs perceived that MHPs did not always have adequate skills to manage the aphasia

Where does all this leave people with aphasia?

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Schemes and therapies to support QoL & HRQL: work at City University London

LUNA project (Cruice et al.)

EVA Park (Marshall et al.)

SFBT (Northcott et al.)

Peer befriending (Hilari et al.)

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LUNA (Cruice, Dipper & Knight)

- Language Underpinnings of Narrative in Aphasia
- Brings language and discourse together with identity.
- 7 weeks of therapy
- Student delivered

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Pilot work

- Pilot with 5 PwA to enable them to tell their stories.
- Double baseline (T1, T2), 7 weeks Trx, post-testing (T3), 5 wks break, follow-up testing(T4)
  - Stories: personally relevant. E.g., about things they've done, places they've been to, and events which are important to them.
  - Work with them to *develop* their stories
    - Revising and choosing words and sentences
    - Story structure
    - Mapping
    - Multimedia

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Aims and Outcome measures

1. Change in micro- & macro-linguistic features of the participant's personal narrative (treated)

   (narrative words, verb type & token, argument structure, complete utterances, discourse connectives, local coherence)

2. Change in micro-linguistic & macro-linguistic features of the participant's discourse (Cinderella; untreated; as above)

3. Impact on the participant's
   - communication confidence (CCRSA: Babbitt et al., 2011
   - mood (GDS: Sheikh & Yesavage, 1986) and
   - social networks (Social network: Antonucci & Akiyama, 1987)

Stories with aphasia

EVA Park

Slides with thanks to Jane Marshall

- Jane Marshall, Tracey Booth, Niamh Devane, Julia Galliers, Richard Talbot, Stephanie Wilson, Celia Woolf
- Virtual communication environment for PwA
- Will access to the environment:
  - improve participants' communication skills?
  - improve communicative confidence?
  - reduce social isolation?

EVA Park

- Co-designed with 10 consultants with aphasia
- An enclosed island built with Open Sim
- Contains distinct regions, e.g.:
  - Houses
  - A Cafe
  - A Tropical Bar
  - A Versatile Counter (e.g. for booking a holiday)
  - A Health Centre
  - A Hair Dressers
  - A Disco

Intervention

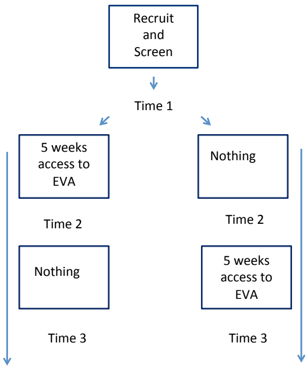
- 20 people with aphasia had access to EVA Park
  - 5 weeks intervention
  - Daily sessions with support workers
  - Personal goals/programme of activities
  - Unlimited independent access
  - Pre and post intervention testing

Examples of Goals

- Breaking messages down into manageable segments
- Coping with specific situations, such as:
  - A doctor's appointment
  - Speaking to a receptionist
- Talking in groups
- Giving a speech

Examples of Activities

- Role plays
  - Ordering a drink
  - Getting a hair do
  - Dealing with an incompetent waitress
  - Reporting a suspicious character to the police
- Conversation
  - Education and career history
  - Plans for the weekend
  - Past experiences of travel
  - Wife's trip to hospital
  - Experiences in EVA Park
- EVA Actions:
  - Dancing
  - Visiting the tree houses, boats, light house
  - Fun day (diving, run round the lake and stroke the donkey)



Recruit and Screen

Time 1

5 weeks access to EVA

Nothing

Time 2

Time 2

Nothing

5 weeks access to EVA

Time 3

Time 3

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Range of Outcome Measures

- Communication (next slide)
- Communication confidence (CCRSA)
- Friendships (Friendships Scale)
- People with aphasia views: Qualitative interviews pre and post EVA
  - Experiences of communication
  - Social activities
  - Use of technology
  - Views of EVA

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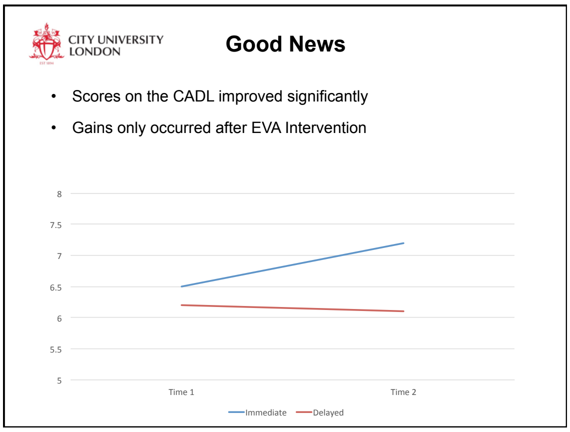
Communication

- Functional Communication: CADL-2 (Holland et al, 1999)
- Word retrieval
  - Fluency test (Supermarket, Airport, Health Centre, Restaurant, School, Cinema, Park, Kitchen, Hair Salon, Sports Stadium)
- Narrative
  - Retell a familiar story: Narrative words per minute
- Conversation:
  - Randomly partnered with SLT student (different student each time)
  - 10 minute sample for analysis



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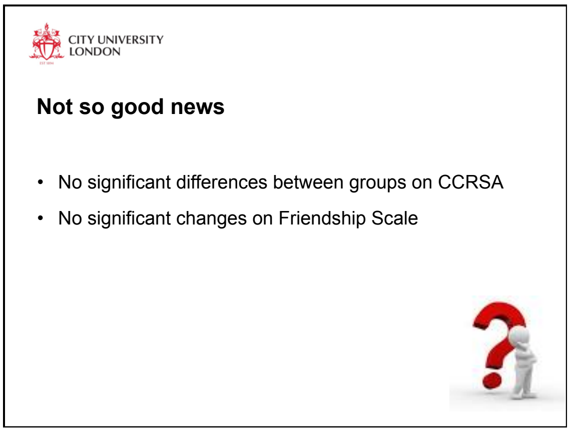
Good News

- Scores on the CADL improved significantly
- Gains only occurred after EVA Intervention



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Not so good news

- No significant differences between groups on CCRSA
- No significant changes on Friendship Scale

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Participants' views about EVA

- 'Wonderful. Well it's wonderful. Well it's all my expectations are real'
- "Brilliant!"
- "The whole experience was something else"
- "On the decking up the top by one of the houses, and I'm thinking 'oh god I'm on holiday here'"
- 'Its been very good. I'm still finding new places to go'
- 'Tried them all. Sat on elephant. Swam on turtle. Dancing in Tardis and disco.'
- 'Cut and dyed A's hair. Drunk. Played on the diving board. Had pizza. Had band.'
- 'Fantastic. Chatting.'

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Views of Family Members

- 'When we go to church, he's more **CONFIDENT** in having conversations with people, whereas before he would hold back more. Now he's been more spontaneous. Talking about sports etc and I know he's been talking about the same topics in EVA Park. He's had a practice so he's extending what he's talking about outside.'
- 'He **ENJOYS SOCIAL CONTACT** – talking to another person who's very good at listening to him. And the sillyness – like the diving board. (He was) disappointed when the mermaid didn't talk back'

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EVA Park

- http://smcse.city.ac.uk/eva/?page_id=577
- See article http://www.huffingtonpost.co.uk/lucy-maddox/speech-recovery-technology_b_8512246.html
- Watch video https://www.youtube.com/watch?v=ouF1Nwvo6js&feature=youtu.be

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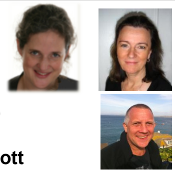

Solution Focused Brief Therapy
(Northcott, Burns, Simpson, & Hilari)

- **Slides with thanks to Sarah Northcott**
- Is it possible to adapt SFBT so that it is communicatively accessible for people with aphasia?
- Will SFBT enhance
  - emotional well-being?
  - social well-being?

(Northcott et al., in press *Folia Phoniatrica et Logopedica*)

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What is the evidence base for SFBT?

Gingerich, W. J., & Peterson, L. (2012). Effectiveness of solution-focused brief therapy: a systematic qualitative review of controlled outcome studies. *Research on Social Work Practice, 23*(3), 266-283.

- 43 controlled outcome studies
- 74% reported significant positive results, while 23% reported positive trends
- The strongest evidence of its effectiveness was in treating adults with depression, where it was comparable yet briefer and therefore less costly than alternative approaches

Not yet been evaluated as an intervention for people with aphasia

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What is Solution Focused Brief Therapy?

- An approach to building change
- Encourages a person to describe their 'preferred future', (what will be different when they start moving in the direction they want?)
- It explores what a person is already doing that is working
- It helps people to notice signs of change (what have they been pleased to notice?)

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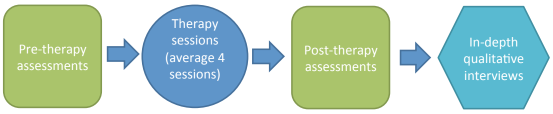
Feasibility study design



Pre-therapy assessments → Therapy sessions (average 4 sessions) → Post-therapy assessments → In-depth qualitative interviews

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Participants

Pseudonym	Age	Living situation	Years post stroke	Total FAST score	Care arrangements
Al	60	On his own	7 (1st stroke); 4 (2nd stroke)	22/30	Daily carer
Bayya	63	On his own	4	21/30	Daily carer
Colin	58	With wife and son	2	27/30	Wife main carer
Delia	45	With young child	14	15/30	Daily carer
Edith	73	On her own	4 (1st stroke); 2 (2nd stroke)	18/30	Independent

Key outcomes of the completed study

- Acceptable
- Improved mood
  GHQ-12 (Goldberg, 1972)
  Pre-therapy: mean (SD) = 4.80 (4.60); median (IQR) = 6 (0-9.00)
  Post therapy: mean (SD) = 2.0 (2.55); median (IQR) = 1 (0-4.50)
  Cohen's *d* = 0.79
- Improved participation
  Communicative Participation Item Bank (Baylor et al., 2013)
  Pre-therapy: mean(SD) = 7.80 (5.76); median (IQR) = 7 (3.0-13.00)
  Post therapy: mean (SD) = 12.20 (4.44); median (IQR) = 14 (8.0-15.50)
  Cohen's *d* = 0.80

Qualitative evidence: increased confidence

All participants **more confident to talk**

More confident to do **everyday activities** independently

Improvements in mood

Peer befriending

- New study planned to start April 2016
- 2016-2019, 3½ year project
- Team: Hilari K (CI), Marshall J, Simpson A, Thomas S, Flood C, Northcott S, McVicker S, Goldsmith K
- Single blind, multiple methods, parallel group phase II RCT comparing peer-befriending vs. usual care, starting at discharge from hospital.
- Further information from k.hilari@city.ac.uk

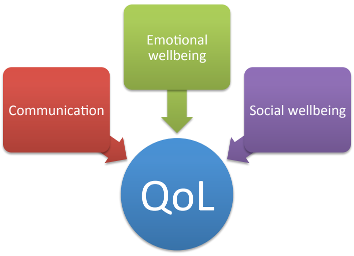
Aims

- 1. Explore the feasibility of a definitive/phase III RCT on clinical and cost-effectiveness of peer-befriending for people with aphasia post-stroke.
- 2. Measure psychological and social wellbeing outcomes of participants, significant others, and peer befrienders.
- 3. Explore the economic consequences of peer befriending versus usual care control.

Methods

- Four work packages
  - Development phase [intervention manual; fidelity; OMs; befrienders training; pilot]
  - RCT [n=60]
  - Qualitative study
  - Economic Evaluation

So… to address QoL / HRQL in aphasia


Emotional wellbeing

Communication

Social wellbeing

QoL

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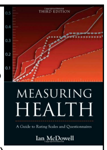
What measures to use for QoL outcomes?



Refer to McDowell (2006)

- Domain specific (e.g. depression, social network, participation)
- Condition specific (e.g. stroke, TBI)
- Generic

For specific domains - e.g. for emotional well-being / depression

- General Health Questionnaire GHQ 60, 28, 12 item versions (Goldberg, 1972; Goldberg & Williams, 1988)
- Geriatric Depression Scale (Yesavage et al., 1983) – GDS 15 & 30 item
- Beck Depression Inventory (Beck et al., 1996)

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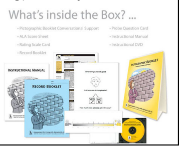
What HRQL / QoL outcome measures to use in aphasia?

Most widely tested in aphasia – including sensitivity to change:

- Burden of Stroke Scale (BOSS) Refs by Doyle PJ et al 2003, 2004, 2007 and others
- Stroke and Aphasia Quality of Life scale (SAQOL-39g) Refs by Hilari et al., 2003, 2009 and others

* Watch out for new assessment - ALA



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We need more research

- Interventions that aim to improve HRQL for people with aphasia by specifically targeting factors that affect HRQL, such as depression, engagement in activities, and diminishing social networks. See
  - Thomas et al, 2013 Communication and Low Mood (CALM) study
  - Biographic narrative approach (Corsten et al., 2013)
  - Dialogue based approach (Bronken et al., 2012)
  - Solution Focused Brief Therapy (SFBT) for people with aphasia (Northcott et al., in press Folia Phoniatrica et Logopedica)
- Interventions driven by priorities by those who live with aphasia and consensus amongst clients, clinicians, researchers, commissioners/ funders, and policy makers
  - Core Outcome Sets (Wallace et al., 2014)

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Thank you ☺

Questions?